The Lung Infection PCP

How to Help Yourself

National Institutes of Health

National Institute of
Allergy and Infectious Diseases

What is HIV Disease?

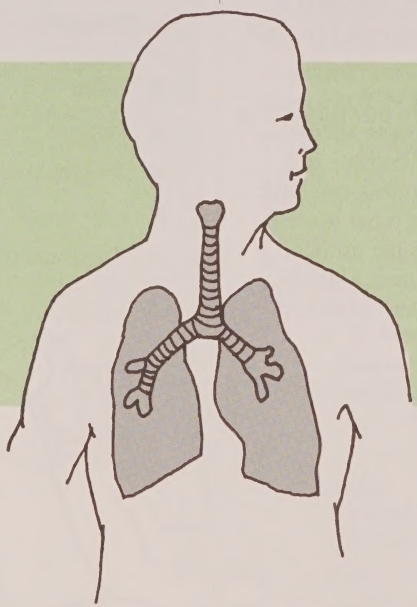
HIV means **H**uman **I**mmunodeficiency **V**irus, which is a germ that can enter the body and cause AIDS (**A**cquired **I**mmune **D**eficiency **S**yndrome). HIV attacks and kills certain cells of the body, especially those that protect us from disease. When too many of these cells have been destroyed, the body becomes weak and the person gets sick. A person with HIV may get very serious diseases that healthy people do not get, such as a rare kind of pneumonia (a disease of the lungs) or some types of cancers. When a person with HIV has one of these diseases, we say the person has AIDS.

Even if they do not look or feel sick, people with HIV can pass the virus to other people by having sex and by sharing needles for injecting drugs. Pregnant women can also pass HIV to their babies before they are born.

This booklet was prepared with the assistance of
the Public Education Technical Transfer Program of the
Community Constituency Group, a committee
of the NIAID AIDS Clinical Trials Group.

PCP: What You Can Do

Many people with HIV, the virus that causes AIDS, get sick with a lung infection called PCP. This booklet explains what PCP is. It also talks about medicines that help prevent and treat PCP—and what you can do to help yourself.



What Is PCP?

PCP is an infection that clogs the lungs, making it hard to breathe. PCP is short for *Pneumocystis carinii* pneumonia, the medical name for this infection. PCP can be severe, but today's medicines can help you fight the disease.

The cause of PCP is a germ that many people already have in their bodies. It is harmless—unless you have HIV or some other disease that weakens the immune system. Without a strong immune system to protect you, the germ can cause a very serious lung infection.

Some or all of these signs may mean you have PCP.

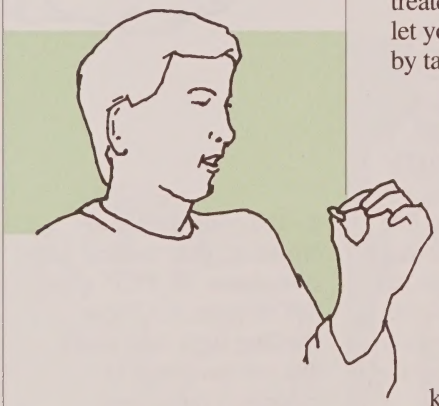
Symptoms of PCP

- Fever
- Fatigue
- Weight loss
- Dry cough
- Shortness of breath.

Medicines Can Help

Research has found medicines that can help against PCP in several ways:

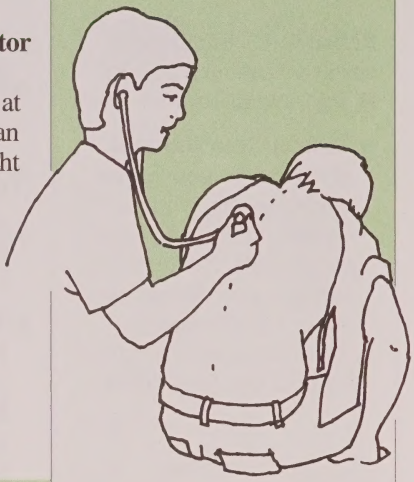
- **To keep your immune system stronger.** Some medicines can help the body fight disease for a longer time. To keep you healthy, your doctor may ask you to start taking medicine as soon as you find out you have HIV.



- **To prevent or delay PCP.** Many people who have not yet had PCP can take medicines to help prevent or delay it. You might begin taking the medicine when blood tests show that your immune system is getting weak.
- **To help you get over PCP.** If you have PCP, you will need to go to the hospital or doctor to be treated. The doctor might let you be treated at home by taking pills.
- **To keep PCP from coming back.** Once you have had PCP, you could get it again. Taking special medicine regularly—such as Bactrim® or Septra®— may help keep PCP from coming back.

How To Help Yourself

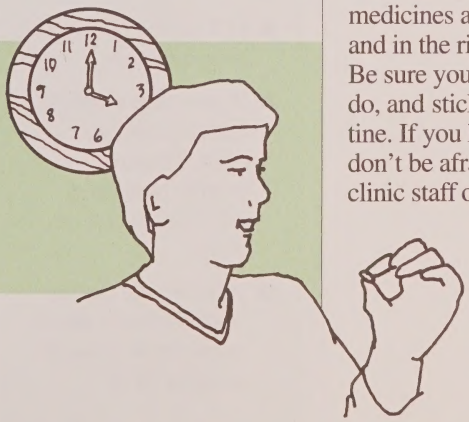
1. Go to a clinic or doctor for regular check-ups. Tests can show if you are at risk for PCP. Then you can begin taking medicine right away to prevent it.



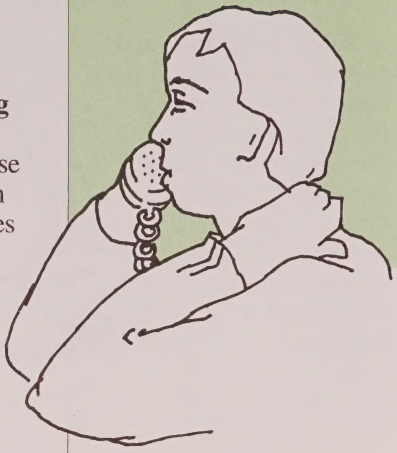
2. Tell your doctor or clinic if you notice any symptoms of PCP (See box on page 2). These warning signs may mean that you need tests or medicines right away.

3. Keep your immune system as strong as you can. This means eating healthy foods, getting enough rest and exercise, and staying away from alcohol, cigarettes, and drugs. It also may mean taking medicine even when you feel well.

4. Follow your care plan if you do get PCP. You will need to take your medicines at the right times, and in the right amounts. Be sure you know what to do, and stick with the routine. If you have questions, don't be afraid to ask the clinic staff or your doctor.



5. Report any new problems that occur while you are taking medicines for PCP. Your medicine may cause side effects, such as skin rash or fever. Sometimes changing the amount or kind of medicine can help.



Remember:

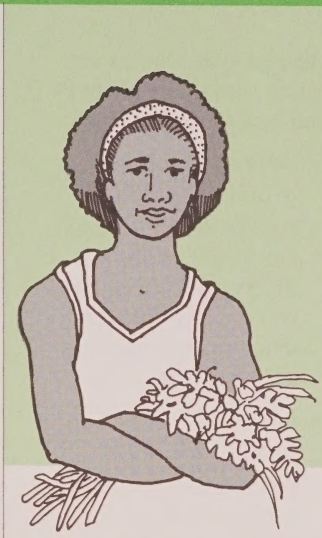
- PCP is a very serious lung infection.
- If you have a cough that does not go away, fever, or trouble breathing, call your doctor or clinic.
- Talk to your doctor or clinic nurse about medicine to prevent or delay PCP.

Research: Hope for the Future

Scientists have made progress against PCP, but they are still looking for better ways to prevent and treat PCP.

Today, many new drugs are being tested. You may be able to take part in one of these tests. If a new drug works, you may help yourself and others with HIV.

If you are interested, talk to your doctor or clinic. Or call the numbers on the next page to find out more.



To Find Out More About PCP

Here are some numbers to call to learn more about PCP and how to help yourself:

- **1-800-342-AIDS**
  (1-800-342-2437)

  You can get more details about PCP and how it affects people with HIV. You can also find out about treatment centers and other help.

- **1-800-TRIALS-A**
  (1-800-874-2572)

  You can find out about testing new drugs for PCP— which drugs are being tested, where the studies are taking place, and who is doing the research.

- **1-800-AIDS-NIH**
  (1-800-243-7644)

  Call Monday through Friday from 12:00 p.m. to 3:00 p.m. (Eastern Time) to find out about studies being done at the National Institutes of Health (NIH) Clinical Center.

Other booklets in this series:
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The Brain Infection TOXO
HIV-Related TB

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NIAID Office of Communications
(301) 496-5717

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health
Bethesda, MD 20892

NIH Publication No. 93-3325
April 1993

CMCC AIDS CARE TEAMS

A Care Team is composed of 10-12 trained individuals working together as a team to care for a person living with AIDS.

Typically the following types of services are provided:

Personal care Transportation
Emotional/social support
Food assistance Spiritual support
Advocacy

Each PLA is different. CMCC services will be provided based on the talents, time, and gifts of the Team.

If interested, please fill out and put in offering plate or give to Shirley Lambert or Shannon Brier.

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Phone no. (H)_____
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List three possible dates and times available for meeting to discuss CARE TEAMS in more detail.

1._____

2._____

3._____

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AIDS-Related

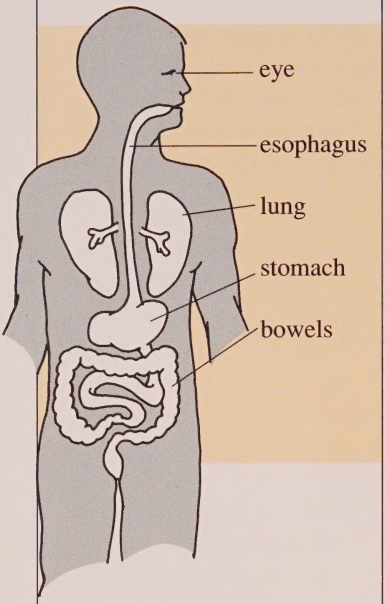
CMV

How To Help Yourself

National Institutes of Health

National Institute of
Allergy and Infectious Diseases

Symptoms of CMV



CMV disease can damage many parts of the body, including the digestive system and lungs. CMV disease most commonly affects the eyes and can cause blindness if it is not treated.

A blood test can be used to find out if you have CMV in your body. Other tests may be used to make sure your symptoms are caused by CMV. An eye exam can show CMV even before symptoms appear.

CMV may cause some of the symptoms listed in the box below:

Symptoms of CMV eye disease

- floating spots before the eyes
- hazy vision, as if looking through a screen
- blurred or missing areas of vision

Symptoms of CMV digestive disease

- diarrhea
- loss of appetite
- fever
- blood in the stool
- stomach cramps
- weight loss
- painful swallowing
- pain in center of the chest

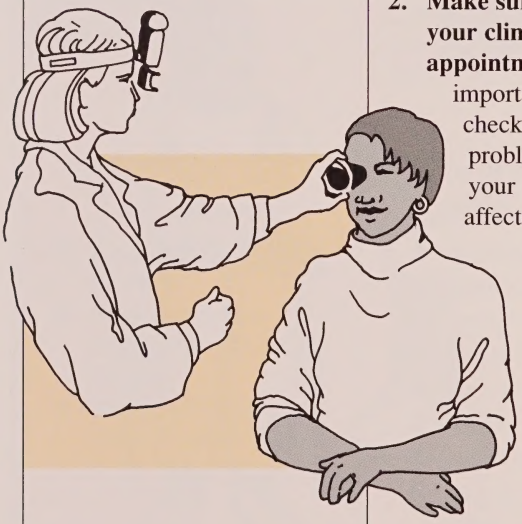
Medicines Can Help

Some medicines can help to fight CMV disease. Medicines can be used to:

- **Keep your immune system stronger.** Certain medicines can help the body defend against disease. To keep you healthy, your doctor or clinic nurse may ask you to start taking medicine as soon as you find out you have HIV.
- **Treat the infection.** There are two medicines that may keep CMV disease from getting worse (ganciclovir and foscarnet). These medicines are injected into a patient's veins. Once you get CMV disease, you may need to continue taking medicine to prevent CMV disease from coming back.

How To Help Yourself

1. **Keep your immune system as strong as you can.** Eat healthy foods. Get enough rest and exercise. Don't use alcohol, cigarettes, and other drugs.



2. **Make sure you keep your clinic appointments.** It's important to get regular checkups to ward off problems BEFORE your eyesight is affected.

3. **Tell your doctor or nurse about any symptoms of CMV.** Sudden changes in vision are important warning signs that should be checked out right away. See box on page 2.

4. **Follow your care plan.** Take all your medicines as they are prescribed (at the right time and in the right amounts). Be sure you know how to take them. Ask your doctor or clinic nurse if you have any questions. Continue to keep your clinic appointments so that your doctor can check you to make sure that the medicine is working.

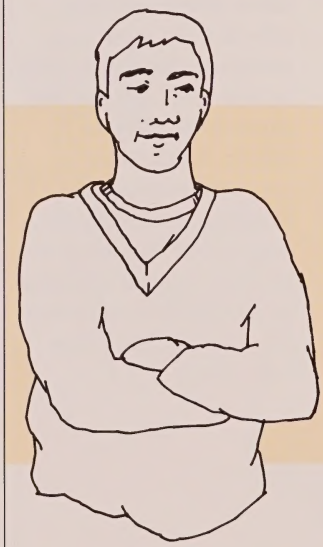
5. **Tell your doctor or clinic nurse about any side effects from your medicine.** Medicines used to treat CMV disease can cause fever, diarrhea, nausea, tiredness, or abnormal bruising and bleeding in some people. Your doctor may have to give you another medicine or change the amount that you take to reduce your side effects.

Research: Hope for the Future

Scientists are working to find better drugs to treat and prevent CMV disease. Drugs that may work better and are easier to take than the drugs that are now used are being tested in research studies.

You may be able to help test one of these new drugs. If you take part in research, you may help yourself—and others with HIV.

If you are interested, talk to your doctor or clinic nurse. Or call the numbers on the next page to find out more.



Remember:

- CMV is a serious disease that can cause blindness and damage to other organs if not treated.
- Tell your doctor or clinic nurse right away if you have sudden changes in vision or other symptoms of CMV disease.
- Take your medicine as your doctor prescribed.
- Be sure to have regular checkups.

To Find Out More About CMV

Here are some numbers to call to learn more about CMV and how to help yourself:

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  (1-800-342-2437)
  You can get more information about CMV disease. You can also find out about treatment centers and other help.
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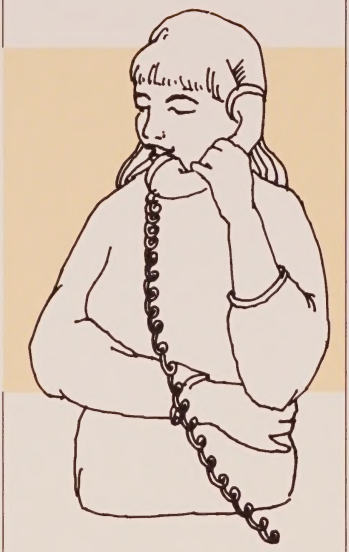

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October 1993

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- NMAC is your national voice. The Public Policy Program brings the latest information on federal legislative and executive actions to communities of color. NMAC staff members hold frequent meetings with Administration and Congressional leaders and NMAC is recognized as a leader among national organizations that work to bring about favorable legislation on funding and civil rights for persons living with HIV.

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HIV / AIDS MINISTRIES NETWORK
FOCUS PAPER # 29

A NETWORK OF UNITED METHODISTS AND OTHERS WHO CARE ABOUT THE GLOBAL HIV/AIDS PANDEMIC AND THOSE WHOSE LIVES HAVE BEEN TOUCHED

ABOUT THIS ISSUE
December 1995

IN FOCUS PAPER # 29

About This Issue **cover**

"The Black Church and the AIDS Crisis" **1**
by Mackie H. Norris

"Resolutions on HIV/AIDS from GBGM Going to General Conference" **11**

"Guidelines for the Interfaith Quilt Project" **18**

Dear Network Members:

This ***Focus Paper*** begins a series which will focus on the issue of HIV/AIDS and the black church. The African American community continues to be disproportionately impacted by HIV. As the center of much of African American life, the black church has a key role to play in ministries with persons living with HIV/AIDS.

This paper includes the two HIV/AIDS resolutions which will be going to General Conference in April of next year. These resolutions originated with the Interagency Task Force on AIDS and will be presented by the General Board of Global Ministries (GBGM) with the endorsment and support of the General Board of Church and Society, General Board of Discipleship and the National Youth Ministry Organization.

The final portion of this paper is a copy of the "Guidelines for the Interfaith Quilt Project" which you may find helpful. We will focus on the Quilt in an upcoming edition of our **Focus Papers**.

Rev. Charles Carnahan
Executive for HIV/AIDS Ministries

HIV/AIDS Ministries Network Focus Papers are a publication of the Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church, Room 350, 475 Riverside Drive, New York, NY 10115. Phone: 212-870-3909. FAX: 212-749-2641. INTERNET: aidsmin@gbgm-umc.org.

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THE BLACK CHURCH AND THE AIDS CRISIS

by Mackie H. Norris

Introduction

The United Methodist Church, as an institution in the African American community, is unique. While its structure reflects the concept of inclusiveness, some racial separation remains. The denomination and its predecessor denominations had to address and overcome the burden of segregation within the church structure itself. This burden, although remnants do remain, is not the problem that it once was because the structure has been changed. However change of official structure does not automatically guarantee that at the level of everyday life the change will be realized. There remain African American Churches in The United Methodist Church.

To be sure, there are many African American churches in many denominational forms. Although there is no one Black Church as a church, the African American (Black) Church can be addressed as a single institution and will be addressed as such in this writing.

Historical Perspective

Historically, the church in the African American community has been the initiator for activities that benefit the African American community. Many scholars, including Lincoln (*The Black Experience in Religion*, 1974), Mays (*The Negro's Church*, 1933), Washington (*Black Religion: The Negro and Christianity in the United States*, 1964), and DuBois (*The Souls of Black Folk*, 1907) have affirmed this idea. In the church, educational opportunities were presented and encouraged; in the African American Church educational institutions for African Americans were born. The church was the cradle where voter registration was nurtured and matured. In the church, economic opportunities were conceived for African Americans.

Mackie L. Harper Norris is a registered professional nurse who has a special interest in community health. She holds a Master of Nursing Degree from Emory University, Atlanta, GA and anticipates receiving a PhD degree in May, 1996. Her area of study focuses on the relationship between religion and health. She is interested in the health of African Americans and how the church can be mobilized to meet the increasing needs. Mrs. Norris is the wife of Bishop Alfred L. Norris, Resident Bishop of the North West Texas-New Mexico Area of The United Methodist Church. They reside in Albuquerque, New Mexico.

The church was the site of the civil rights movement, based on a theology of liberation. Liberation Theology addresses the concern of freedom of oppression, as do African American Theology and Black Theology. (See box for definitions of these theologies on page 3.) Given this history, it could surely be in the African American Church where the major thrust regarding care and nurture for persons with AIDS and the ones that love and support them finds fertility and fruition.

Liberation Theologies and HIV/AIDS

The Black Church, as an institution, came into being following separation from white churches, because the majority church did not confer full status to black people. In the formation of the Black Church, full status to all was conferred. This is significant, especially at a time when other oppressions are keeping people from experiencing the fullness of belonging to the body of Christ. It is incumbent upon the Black Church to remember its own history and, from it, to assure that no group be made to suffer such inhumanities. The function of Liberation Theology is to call people to this remembrance.

Liberation Theology in the African American community was born as a result of the inhumanities black people suffered and are still suffering at the hands of the majority population. The liberation of black people is an ongoing process. It will continue as long as there is real or perceived enslavement. So, too, will Liberation Theology remain.

From the beginning, Black Theology was understood as Christian theology which reflected upon the struggle for justice and liberation. In that light, Liberation Theology was and is not limited to any ethnic group. African American Theology attends to the liberation of African Americans and also brings into sharper focus the contributions of Africans in monotheistic religion.

Liberation Theology can embrace anyone who is struggling under an oppressive state. Such is the case with people who have AIDS or HIV. AIDS in indeed oppressive, not only because of the physical manifestations of the disease but also the social responses to the disease. Within the meaning of liberation stands the inclusion of freedom from all that would impede the strive toward salvation and wholeness.

If the African American Church is to be empowered by a theology of liberation, then persons with AIDS would be included under the umbrella of concern and ministry. Liberation Theology is inclusive, not selective. All persons who are oppressed, for whatever reason, are the concerns of Liberation Theology.

The church must be liberating if it is to live up to the mandate of African American Christianity. African American Christianity should be a tool to direct African American congregations to be particularly mindful of HIV/AIDS because the epidemic is growing most rapidly in the minority population. What was once thought to be a disease of white gay men has become the scourge of minorities, in general, and black women, in particular. Not to be overlooked is the fact that women also make up the majority of church memberships. If so many women are becoming infected by the AIDS virus and women comprise the majority of church membership, then an additional reason for the development of AIDS ministries exists.

Definitions of Theological Terms

African American Theology is theology that affirms the understanding of God through experiences of life in the United States of America as African Americans.

Black Theology is a theology driven by political power as understood by and in the African American community. Its birth was a result of the Civil Rights movement, which energized the power of the African American community.

Liberation Theology is the quest for salvation through the eradication of oppression.

Theology is an understanding of a community's belief in the Divine.

Womanist Theology is the voice of Liberation Theology spoken and understood through the experiences of women. It is a theology that calls to task the sexism that has pervaded all forms of theology.

In addition, the question of HIV disease presenting a threat to one's civil rights has been addressed by some advocates of AIDS awareness. They postulate that when HIV disease is seen as a threat to the civil rights of the individual, the community, and the nation, then perhaps more attention will be given to limiting its effects and ultimately eradicating it.

That HIV disease is a threat to civil rights leads to the necessity of the Black Church to be a liberating institution for African Americans and for all people. Liberation Theology, as stated before, addresses the concept that oppression, in any form, must be eradicated.

Initiating Action

Liberation Theology, a theology of involvement, includes both proximal and contextual action. Proximal action is person-to-person intervention, including actions that provide for the personal needs of the sufferer. Contextual action addresses the systemic causes of enslavement.

In the case of HIV/AIDS, proximal action includes providing housing, food, transportation, health services, and the like. Provision of resources meets the basic needs of life. This gives a face and name to HIV/AIDS. The people affected, whether directly or indirectly, would become the image, rather than the disease. Contextual action includes addressing the problem of AIDS at the systems level. The federal, state, local governments, school systems, health care systems, religious systems, legal systems, corporate systems, and others have all been influenced by the HIV/AIDS epidemic. Schools have attempted to deny access, courts have battled over rights, health care has been overloaded with needs without available resources to meet them. Contextual action means calling these, and other, systems to the task of providing the resources, means, attitudes, and environment in which the HIV/AIDS epidemic could be addressed and eliminated.

Contextual action includes the church when the church itself is operating under polarizing beliefs about the meaning of HIV/AIDS. Liberation Theology, for the church, means confronting the systems that continue to persuade the general population that the presence of HIV/AIDS is God's way of calling people to repentance for their sinful life styles/behavior choices. It also means confronting issues related to suffering.

In the New Testament, suffering is addressed at three levels, in terms of action responses. For example, suffering may be the result of oppression by one person or group of another person or group. This type of suffering calls for contextual action, to confront the oppression at the systems level. The second type of suffering is related to physical or mental disability or disease. This type of suffering cries out for proximal action, action at the personal level.

Types of suffering and action are not always clear cut and simply defined however. When intervening at either the personal or systems level, one may experience unfavorable reactions and responses. According to the scripture, if persecution or alienation occurs when taking liberating action, then a third type of suffering is experienced. This suffering is the result of attempting to live up to the model of compassion, which is the cornerstone of theology in general and Liberation Theology in particular. One cannot engage in acts of true liberation without compassion.

Contextual and proximal action and compassion are the foundation of African American, Black, or Liberation Theology. Place these within the functions of the larger church relative to AIDS-- service, prophesy, and communion. There you will find the responsibility and the opportunity, for theology in general and Liberation Theology in particular, to respond to the crisis that the presence of HIV/AIDS has created.

A Societal Response to AIDS

In some form or another, all of society has been affected by the HIV/AIDS epidemic. According to Dorothy Nelkin in *A Disease Of Society,* "AIDS is no ordinary epidemic. More than a devastating disease, it is freighted with social and cultural meaning" (Nelkin 1991, *et. al.*, p.1). AIDS has become what French anthropologist Marcel Mauss called "a social phenomenon -- one whose transactions are at once economic, juridical, moral, aesthetic, religious, and mythological, and whose meaning cannot, therefore, be adequately described from the point of view of any single discipline" (Bosk and Frader in Nelkin 1991 p. 150).

A social response to AIDS and HIV distinguishes disease from illness. According to Arthur Kleinman, a disease "is an abnormality in the structure and function of the body organs and systems" (Kleinman 1978, p. 252). Illness, on the other hand, refers to "experiences of disvalued changes in states of being and in social function; the human experience of sickness" (*Ibid*). Kleinman goes further to say that both disease and illness are manifestations of sickness. Sickness must receive attention if the patient, whether individual, group, or society, is to have any hope of complete recovery or peaceful death.

Peter Conrad has also described the difference between disease and illness. He states that "disease is understood best as a biophysiological phenomenon, a process or state that affects the body. Illness, by contrast, has more to do with the social and psychological phenomena that surrounds the disease. The world of illness is the subjective world of meaning and interpretation; how a culture defines an illness and how individuals experience their disorder" (Conrad 1988, p. 52).

In relation to HIV and AIDS, the distinction between disease and illness becomes clear in the public's responses to persons living with AIDS and others with whom they interact. According to Morris Floyd, the "responses of a terrified public, misinformed or inadequately informed about the ways in which AIDS spreads, have caused some observers to suggest that hysteria about the malady may be an even greater threat than the virus itself" (Floyd 1986, p. 19).

AIDS, Health Care, and the Church

C. Eric Lincoln has said of the Black Church: "Beyond its purely religious function, as critical as that function has been, the black church in its historical role as lyceum, conservatory, forum, social service center, political academy and financial institution, has been and is for black Americans the mother of our culture, the champion of our freedom, the hallmark of our civilization" (Lincoln 1974, p. 5). An institution with a strong

heritage such as this also has the capability of influencing other institutions through the theology that has directed and fortified it. Therefore today the church can focus on the health care delivery system.

According to Kenneth Vaux, the practice of medicine was, at first, a moral enterprise. As the idolatry of technology gained strength, the profession moved further and further away from the meaning of its inception (Vaux 1985). Currently, the guiding values of health care decisions tend to be based more on economics and technology rather than on compassion, morality, or a holistic understanding of health.

The dynamics of wholeness, or holistic health care, are to work toward unity and integration of the self, others, and the creator. "Whole person care" means the treatment of mind, body, and spirit. Healing means "to touch with love that which we previously touched with fear." It does not mean curing. Necessarily, it means to embrace the situation with an understanding of the finiteness of humankind and the infinite nature of the Creator.

Today's health care delivery system has technology that can perform many feats which were unthinkable just a few years ago. Multiple organ donation and transplantation are an illustration. In addition, in this country, the health care industry has taken on a life of it own. Health care is "driven" by economics. For example, much of our fiscal resources are used to erect larger and larger diagnostic facilities. Often great attention is focused on how to solve health problems but less attention on how to prevent health problems in the first place.

Moreover the focus of medicine as a profession has shifted from the needs of the patient to the rights of the physician. In the case of HIV/AIDS, for example, there is established a policy that the physician has the right to provide the needed care or to refer the patient to another source of treatment. As long as physicians are given this choice of rights in addition to responsibility and as long as our society remains a litigious society, the moral obligations of health care, as defined above in terms of holistic health and compassion, will be secondary.

It is incumbent on another institution to give direction to the health care enterprise. People of faith, especially African Americans, have the opportunity and responsibility to continue to call attention to the liberating effect of focusing on health, not illness; on ethical decision making, not on fiscal or technological decision making; and on obligations that are for the good of the community (the body of Christ), not solely for the individual.

African American and Black Theologies, out of their understanding of the meaning of

liberation, can influence the health care delivery system in its attempt to structure a moral enterprise. Liberation Theology equips people with resources necessary for responsible behavior and nurturing care. It calls for individual and corporate examination, education and training, and clarity of purpose. Earlier in the history of health care, many hospitals, schools of nursing and medicine, were initiated by churches or church-related institutions. We are no longer in need of more medical schools and nursing schools, but we are in need of institutions to focus, again, on what health means to the individual, not the institution.

"One basic distinction of Liberation Theology is an unwavering faith in the absolute sovereignty of the supreme, infinite creator," writes Joseph Washington (Washington 1994). The Black Church came into being as a thrust of black people for self-realization, for spiritual creativity, and for worship and celebration. The understanding of spiritual creativity is a significant tool for the Black Church to use as it helps to reformulate the health care industry into a moral enterprise. That there is a power beyond the walls of the hospital is a message that must be repeated and modeled. The church must develop a transcendent vision to guide health care providers.

Liberation Theology has the opportunity to redirect the intention of medicine to a rededication to the high and holy calling of healing as salvation. If African American and Black Theologies are true to the quest for liberation, then their actions and activities will take them into hospital and pharmaceutical board rooms, medical and nursing schools, and biomedical engineering facilities to call to task the ethical and moral obligations of health care delivery.

The day will come when theology, not technology, becomes the frame of reference. The day will also come when the church, in general, and the African American Church in particular, takes the lead in addressing the problem of HIV disease and in developing supportive ministries for the people affected by the disease-- the individual and others that hold the individual in special relationship.

The Price of the Ticket

As we move toward the end of the second decade of the AIDS epidemic, the demographics of AIDS are shifting substantially. AIDS is spreading rapidly in the urban poor. A group extremely familiar with increased vulnerability to health threats is being ravaged yet again- - one that is least capable of handling all of the problems attendant to the presence of the virus.

This fact bodes poorly for the already overburdened systems that support the needs of this population segment. However, this fact offers the strategic opportunity for the

Black Church to offer a haven of support and care to the victims of HIV disease and their support network.

Dr. Emilie Townes, a contemporary voice for Womanist Theology, presents a comprehensive challenge to the African American community. In her article, "The Price of the Ticket," she calls us to the task of "doing our first works over again." Dr. Townes believes that the AIDS crisis challenges us to take an inward look at our own racism, sexism, and heterosexism. She articulates several "prices," for adequately addressing the HIV/AIDS crisis. These prices are: justice, grace, truth (Townes in Susan Davies and Eleanor Haney 1991, p. 71).

Justice, grace, and truth are also tenets of Liberation Theology, Christianity, and Womanist Theology. What we now need is to reclaim those concepts that were the forces enabling the creation of African American Churches.

By all accounts, HIV/AIDS will continue to present challenges to this society previously unmatched by any other crisis. It is, therefore, in the best interest of all of us to participate in education to limit, and ultimately eliminate, the virus. Society must reconstruct the meaning of HIV/AIDS so that the focus will be on the people affected and not the disease. When this happens, society will be more compassionate and churches will be more responsive to the needs of the people living with AIDS.

In a real sense, all of us are already suffering the effects of the disease, because of the societal changes that have taken place. As responsible citizens of the world community we must use our resources, including our influence, to rid the society of this devastating disease. We must model the examples of Jesus, the Christ, as we minister to the needs of today's lepers.

In the words of Rev. Dr. Zan Wesley Holmes, Senior pastor of St. Luke Community UMC of Dallas, TX, "when we know who we are, we will know what to do" (Holmes 1992). When we come to the total realization of what it means to be a Christian, we will become immersed in the struggle. When we accept, fully, the responsibility of liberators through the theology of liberation we will be clear about our mission in the Black Church to confront the menace of AIDS and its associated effects. We seek the power and presence of the Holy Spirit to make it so.

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Two Resolutions on HIV/AIDS
Going to General Conference of The United Methodist Church 1996
from the General Board of Global Ministries

Resolution #1:

RECOGNIZING AND RESPONDING TO THE MANY FACES OF HIV/AIDS IN THE U.S.A.

The United Methodist Church has resolved to minister compassionately with all persons living with HIV/AIDS and their loved ones, following in the way of healing, ministry, hospitality, and service shown by Jesus.[1] Churches and other concerned United Methodist communities have been in ministry since the beginning of the pandemic.

THE CONTEXT OF CARING MINISTRY

HIV/AIDS affects and infects a broad cross-section of people in the United States and Puerto Rico: all ages, all races, both sexes, all sexual orientations. In 1995, the Centers for Disease Control (CDC) noted that the proportion of AIDS cases among women, racial/ethnic people, and children continues to increase, while the rate of AIDS among gay/bisexual men has leveled. From a geographic perspective, more persons in the South and Northeast contracted AIDS in 1994 than in 1993.[2]

The United Methodist Church can help to stop the spread of HIV/AIDS through providing sound comprehensive age-appropriate prevention education, including information that abstinence from sex and injection drug use[3] is the safest way to prevent infection. In addition, the church can provide a grounding in Christian values for children, teens, and young adults, something that cannot be done in public schools or in official government prevention material.

Teens and Young Adults

AIDS will increasingly affect and infect our next generation of leaders. Since 1991, AIDS has been the sixth leading cause of death among 15- to 24-year-olds in the United States. In 1994, 50 percent of new infections of HIV were among persons under 25. Older teens, males, and racial/ethnic people were disproportionately affected.

The CDC reported:

> Many American teenagers are engaging in behaviors that may put them at risk of acquiring HIV infection, other sexually transmitted infections, or infections associated with drug injection. Recent CDC studies conducted every 2 years in high schools (grades 9-12) consistently indicate that by the twelfth grade, approximately three-fourths of high school students have had sexual intercourse; less than half report consistent use of latex condoms, and about one-fifth have had more than four lifetime sex partners. Many students report using alcohol or drugs when they have sex and, in the most recent survey, 1 in 62 high school students reported having injected an illegal drug.[4]

By 1993, HIV became the leading cause of death in the United States among all persons aged 25-44.[5] Racial/ethnic groups have been especially hard hit. By 1991, HIV infection had become the leading cause of death for African Americans and Hispanics among males aged 25-44 years. By 1993, it was the top cause of death for African American women in the same age group. Among Asians/Pacific Islanders and American Indians/Alaska Natives young adults, AIDS ranks in the top ten leading causes of death.[6]

Racial and Ethnic Groups

African Americans, Hispanics, and Native Americans have been disproportionately infected with HIV/AIDS. In 1993, racial/ethnic people accounted for 51 percent of the cases of AIDS among adolescent and adult males, 75 percent among adolescent and adult females, and 84 percent of the cases among children.

Race and ethnicity are not in themselves risk factors for HIV. The CDC observes that "unemployment, poverty, and illiteracy are correlated with decreased access to health education, preventive services, and medical care, resulting in an increased risk for disease. In 1992, 33% of blacks and 29% of Hispanics lived below the federal poverty level, compared with 13% of Asians/Pacific Islanders and 10% of whites."[7] HIV/AIDS prevention education must therefore take into account the racial, cultural, economic realities of each group. Additionally, as the church, we are called to work for the conversion of those principalities and powers that promote racism, poverty, drug addiction, and other oppression.

Women

AIDS among women has been mostly "an invisible epidemic," even though women have been affected and infected since the beginning.[8] Since 1992, HIV/AIDS has been the fourth leading cause of death among U.S. women aged 25 to 44. African American and Hispanic women make up 21 percent of all U.S. women, these two groups accounted for 77 percent of the AIDS cases reported among women in 1994.[9] That same year, the AIDS case rate per 100,000 population was 3.8 for white women; 62.7 for African American women; 26.0 for Hispanic women; 1.3 for Asian/Pacific Islander women; and 5.8 for American Indian/Alaska Native women.

Dr. Michael Merson of the World Health Organization has identified the following reasons for the growing number of HIV infections in women. His observations, though made in the context of global AIDS, are also applicable to women in the U.S.A. and Puerto Rico. He says that (1) women are biologically more vulnerable to heterosexual transmission of HIV and other sexually transmitted diseases (STDs); (2) women tend to marry or have sex with older men, who have often had more sexual partners and therefore are liable to be infected; and (3) women often live in cultures or situations of subordination to men, which often means they cannot insist that their partner use a condom. Merson has said, "Women face extra challenges in protecting themselves and their children from HIV infection. But this vulnerability is hard for women to challenge as individuals, or even through female solidarity alone. It will take an alliance of women and men working in a spirit of mutual respect."[10]

Older Adults

By the end of 1993, persons age 50 and older accounted for 10 percent of all cases of AIDS nationwide.[11] That same year, the increase in persons with AIDS age 60 and older increased 17 percent over the previous year.[12] The most prevalent behavioral risks for older adults are multiple sexual partners and having a partner with a behavioral risk.[13] "The myth that people become sexually inactive as they age has produced dreadful consequences in the age of AIDS."[14]

Most older people believe they are not at risk if they are heterosexual and do not inject drugs. Since they are not worried about pregnancy, older people are less likely to use condoms.[15] One HIV/AIDS social worker says, "Reaching significant numbers of older adults with the HIV prevention message will entail exploring creative venues--the widows' support group at the senior center, the seniors' bowling league, the Gold Age

clubs at community centers and churches. Wherever seniors gather, the HIV message must be visible, accessible, relevant, and respectful."[16]

THE CHALLENGE FOR CHURCH ACTION INTO THE NEXT CENTURY

Churches and other United Methodist organizations need to continue compassionate ministry with persons living with HIV/AIDS and their loved ones. In terms of prevention education, United Methodists have an opportunity to teach not only the facts about HIV transmission and how to prevent infection but also to relate these facts to Christian values. We can do HIV/AIDS prevention education in broader contexts, such as human sexuality and holistic health and addressing societal problems, such as racism, sexism, and poverty. We call on United Methodists to respond.

1. We request that General Board of Discipleship (a) prepare curriculum resources for all age levels that is sensitive to cultural diversity, in consultation with the General Board of Global Ministries and the General Board of Church and Society. The curriculum will include biblical, theological, and ethical grounding, information on what individuals and communities of faith can do in the areas of compassionate ministry and HIV/AIDS advocacy, and age-appropriate comprehensive prevention education, including teaching that abstinence from sex and injection drug use is the safest approach to HIV/AIDS prevention. This material is to be made available in the first half of the quadrennium. (b) revise the United Methodist sexuality curriculum across age-levels to include HIV/AIDS prevention education. (c) prepare worship resources to assist in HIV/AIDS ministry which can be used by both laity and clergy.

2. We call upon the Interagency Task Force on AIDS to coordinate a second national United Methodist HIV/AIDS consultation for the 1997-2000 quadrennium (the first one was held in San Francisco in 1987) in response to frequent requests from individuals, local churches, and conferences for HIV/AIDS training to equip them for ministry in the 21st century. We ask that the event be planned in consultation with appropriate United Methodist racial/ethnic national organizations. The event will equip United Methodist adult and youth to address HIV/AIDS issues and concerns into the 21st century, including the trends noted in this resolution, such as HIV/AIDS and women, youth, children, and cultural and racial diversity. The emphasis will be on HIV/AIDS in the United States but will have a global component.

3. We urge all national leadership training sponsored by general church agencies include an HIV/AIDS education awareness component, basic facts about HIV/AIDS, workplace issues when appropriate, and ministry concerns.

4. We ask local churches and all United Methodist organizations and communities to respond to the concerns of this resolution through use of the planned resources and materials, such as the United Methodist HIV/AIDS Ministries Network Focus Papers, and working with religious and/or community-based HIV/AIDS organizations to do prevention education with church and community. The United Methodist Church has a congregational HIV/AIDS ministry called the Covenant to Care Program, whose basic principle is "If you have HIV/AIDS or are the loved one of a person who has HIV/AIDS, you are welcome here...." We commend those who have been in ministry through this program and recommend A Covenant to Care to all United Methodist organizations.[17]

ENDNOTES

1. "AIDS and the Healing Ministry of the Church," General Conference 1988.

2. CDC, "Current Trends: Update, Acquired Immunodeficiency Syndrome--United States, 1994," 02/03/95.

3. By injection drug use, we are referring to sharing of needles and works done by injection drug users. Usually this refers to use of heroin on the streets or steroids in sports contexts. We are not referring to persons who are diabetic, for instance, who use only sterile needles and inject insulin to maintain health.

4. *CDC Hotline Training Bulletin #114*, 01/06/95.

5. *Morbidity and Mortality Weekly Report [MMWR]*, 02/03/95.

6. *MMWR*, 09/09/94.

7. *MMWR*, 09/09/94.

8. See Gena Corea, *The Invisible Epidemic: The Story of Women and AIDS* (New York: HarperCollins, 1992).

9. CDC Fact Sheet, "Facts about. . . Women and HIV/AIDS," 02/09/95.

10. Press release published in Edinburgh, England on September 7, 1993 during the 2nd International Conference on HIV in Children and Mothers.

11. National Institute of Health, "Older Americans at Risk of HIV Infection Take Few Precautions," 01/04/94.

12. *New York Times*, 08/09/94.

13. NIH, "Older People," 01/04/94.

14. Gregory Anderson, "HIV Prevention and Older People," *Siecus Report*, December 1994/January 1995), p. 19.

15. Rebecca A. Clay, "AIDS Among the Elderly," *Washington Post*, 01/16/93.

16. Anderson, p. 20.

17. For more information about the Covenant to Care program and HIV/AIDS ministries resources contact:

HIV/AIDS Ministries Network
Health and Welfare Ministries, General Board of Global Ministries, The United Methodist Church
Room 350
475 Riverside Drive
New York, New York 10115

Resolution #2

WORLD AIDS DAY OBSERVANCE

Each year, World AIDS Day is observed on December 1. It is a time for special programs on HIV/AIDS education and religious worship services that focus on intercessory and healing prayer, hope in God, and love and compassion in the midst of the HIV/AIDS pandemic.

We recommend that United Methodists be encouraged to observe World AIDS Day on or around December 1. We further recommend that voluntary offerings may be channeled through the Advance Special for HIV/AIDS Ministries (#982215-6). We ask that the Advance Committee include information in a mailing about World AIDS Day (December 1), which may be used as a vehicle for raising United Methodist awareness of ministries addressing this issue.

Materials for World AIDS Day are available each year from the World Health Organization, the General Board of Church and Society, and the General Board of Global Ministries, the United Methodist Church.

THE NAMES PROJECT FOUNDATION

AIDS Memorial Quilt

Guidelines for the Interfaith Quilt Project

Bringing the AIDS Memorial Quilt into your religious community is a special opportunity to encourage reflection and education around the issues of HIV and AIDS. This is a time to show support for those in your community affected by the epidemic, to offer care for people with AIDS, to remember loved ones, and to reflect on death and dying. The Quilt, like holy objects and rituals in many religions, is cherished by the thousands of panelmakers who created it and by the families and loved ones of those represented on its panels. A Quilt display in your faith community provides a valuable occasion for enhancing spiritual activity and allows your community to show respect and compassion for those lost to AIDS.

INTEGRATING THE QUILT INTO A FAITH COMMUNITY

In a religious setting, a display of the Quilt can be a powerful symbolic, visual, and emotional experience. With this in mind, many congregations choose to expand the Quilt's role in their community. The following are a few ways to welcome the Quilt into your congregation:

- Form a host committee to coordinate spiritual, educational, and memorial components of your Quilt display.
- Invite local groups such as other congregations and interfaith organizations, school groups, HIV/AIDS and other health organizations, community based organizations, educational organizations, and arts organizations to visit the panels during special hours; or schedule an open house and invite the community.
- Incorporate the Quilt display into services or special ceremonies to encourage reflection and discussion. (See **Guidelines for Religious Ceremonies** for more information.)
- Integrate the Quilt into congregational activities such as educational programs, social action groups, or special holiday programs.
- Invite religious leaders from other denominations and organizations to attend the display.
- Organize discussions around the Quilt and HIV/AIDS awareness; develop educational activities for members of the congregation, including youth.
- Plan and hold a panelmaking workshop.
- Provide a book, registry, or signature square for members and visitors to record their impressions of the Quilt and other feelings related to HIV and AIDS.
- Inform the congregation of how your faith has responded to the AIDS epidemic
- Encourage participants to become involved in faith or community based AIDS service programs or organizations
- Suggest panelmaking for your community; invite a local panelmaker to speak at your ceremony
- Contact the NAMES Project Foundation's education coordinator for ideas about additional educational programs.

310 Townsend Street, Suite 310, San Francisco, CA 94107. Tel:415/882-5500 Fax:415/882-6200
Visitor Center & Panelmaking Workshop: 415/863-1966, Fax: 415/241-7936

CARING FOR THE QUILT

The Quilt is a unique and fragile memorial; the delicate nature of the fabric panels requires that it be treated with respect and careful attention. Remember that the Quilt is never cleaned and cannot be replaced. In religious settings, some special care should be taken when displaying the Quilt:

- Holy water or other liquids may not be sprinkled over the Quilt.
- While a candle lighting service can be a powerful ritual to welcome the Quilt to your community, remember to keep candles far from the actual Quilt panels.
- Although incense may burn regularly in your place of worship, do not use incense on or near the Quilt.
- The Quilt may not be placed on or draped over an altar or area where religious objects are displayed; do not display panels over direct air vents or near open doorways where air currents may create Quilt movement.

Strategic placement of the Quilt in a congregational site will accentuate its visual effect; some groups have placed Quilt panels on the wall beneath a choir loft or in the light of a stained glass window for a memorable impact.

RELIGIOUS RITUALS AND QUILT DISPLAY

Ceremonies or activities around the Quilt's visit that incorporate some of your congregation's traditions can contribute greatly to the profound impact of a Quilt display. At the same time, it is important to recognize that panelmakers and people represented on Quilt panels come from many different faiths. The NAMES Project Foundation asks that congregations not bless Quilt panels or pray for people represented in the Quilt; or perform religious rituals with the Quilt. Interfaith ceremonies are permitted and encouraged.

Congregations submitting new panels may bless or include their panels in religious ceremonies if the panelmakers wish, since these panels are not officially part of the Quilt yet. New panels may be draped over an altar or placed in an area where religious objects are displayed.

Star light... star bright... first star I see tonight...

ONE NIGHT STAND UP '94

BIRMINGHAM AIDS OUTREACH

May 7, 1994 • VIP RECEPTION - 7:00 PM • GALA - 8:00 PM

OFFICIAL PROGRAM AND ANNUAL REPORT

ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

Not For One Night Only

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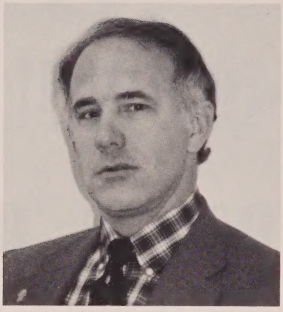
ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

Introduction



Sam Thompson, Executive Director

The AIDS epidemic affects all the citizens of Alabama. In December 1993, the Alabama Department of Public Health reported a total of 2406 diagnosed AIDS cases in the state. Jefferson County reported 733 cases, just over 30% of the state total. An estimated ten times this number of Alabamians are HIV positive.

In 1993 Birmingham AIDS Outreach provided direct services to more than 280 individuals and made information and education available to thousands more. Since 1985 BAO has provided direct service to more than 600 men, women and children. These people are the reason we exist, the reason why we undertake special events such as ONE NIGHT STAND UP.

BAO continues to work with other organizations to identify additional sources of support for people with AIDS in Alabama. In 1993 BAO contracted with Meals on Wheels to provide home delivered hot meals for people living with AIDS. In collaboration with Children's Aid Society we have begun "The Family Pairs" project. This is a joint effort to identify, recruit, train and support foster parents to care for the growing number of AIDS Orphans.

Birmingham AIDS Outreach also continued its efforts to raise awareness while raising much needed revenue. In October the second annual "FOR ALL WALKS OF LIFE" AIDS walk drew over 5000 participants. Alabamians of all ages and ethnic backgrounds, parents and children, employers and employees, people from Huntsville to Mobile, came together in downtown Birmingham to acknowledge that AIDS is an important issue in this state.

On World AIDS Day 1993 BAO and other AIDS service providers conducted various events to raise awareness, while remembering those who have lost their lives to the epidemic. The U.S. Postal Service unveiled the AIDS awareness stamp. In partnership with the Birmingham Museum of Art, a "Prayer Gate" was created by artist Martha Posner which gave us the opportunity to reflect on what we have accomplished and to acknowledge that much more is left to do.

In the pages that follow we hope to provide you with answers to questions about Birmingham AIDS Outreach. We invite you to share our vision and to stand with us as we face the challenges of the future. With your help we shall continue to respond with compassion and creativity to the needs of everyone affected by AIDS.

Sam Thompson
Executive Director

Smith Williams
Chair, Board of Directors

ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

What is BAO?

HISTORY

BAO is a social service agency, governed by a volunteer Board of Directors, guided by the following mission and goals.

MISSION

The mission of Birmingham AIDS Outreach is to improve the quality of life for people affected by HIV through direct services, advocacy, and education.

GOALS:

1. To provide direct services to those affected by HIV.
2. To serve as an advocate for people affected by HIV.
3. To provide education programs that intercede in the spread of HIV and to foster a humane response to persons affected by the epidemic.
4. To develop an adequate and diversified funding base.
5. To develop a responsible and accountable organization.

ABOUT BAO

Location:
205 32nd Street South
Birmingham, AL 35222

Mailing Address:
P.O. Box 550070
Birmingham, AL 35255

Office Hours:
Monday-Friday, 9 a.m. to 5 p.m.

AIDS Helpline:
(205) 322-4197
9 a.m. to 10 p.m.
Monday-Friday

Business Office:
(205) 322-0757

FAX:
(205) 322-2131

What is ahead for BAO?

As we look forward to the next 12 months, the Board and staff of Birmingham AIDS Outreach will need your help to continue to find ways to meet the needs of people affected by HIV/AIDS. BAO is currently working with other agencies in the Birmingham area to identify financial resources that we can tap in order to better serve our clients. We constantly evaluate client needs and identify ways to respond. In 1993 we developed a working relationship with Meals on Wheels to make home delivered, nutritional hot meals available to people with AIDS. We have joined forces with the Children's AID Society to meet the challenge of children left parentless by this epidemic. We have channeled the concern of the young people in Birmingham, through a Youth Advisory committee, to keep us in touch with the most effective ways to educate and involve those most at risk in our community. We continue to expand our Speakers Bureau and other educational programs in an effort to reach high risk populations as well as inform the general community about issues related to the epidemic.

October 23rd will bring the third annual Alabama Walk for AIDS. We hope to see the number of participants continue to grow and even more revenue raised to benefit Alabama AIDS service agencies. World AIDS Day on December 1st, followed by the BAO Art Auction on December 4th, will offer opportunities to raise awareness and resources for the ongoing work of our organization. The Holiday Gift Box project will again give us a way to send a tangible gift of concern and hope to over 200 people with AIDS in Birmingham and the surrounding area. Mark your calendars and be part of our ongoing effort to reach out to our community.

Dates to remember:

- 3rd Annual Alabama AIDS Walk—October 23rd
- World AIDS Day—December 1st
- "You Gotta Have Art" Auction—December 4th
- Holiday Gift Box Project—November and December

If you need information about these events, please contact the BAO business office at (205) 322-0757

ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

Client Services

Shirley Lambert, MSW

Shirley Lambert, L.G.S.W., and Rick Davis, L.B.S.W., provide client services at Birmingham AIDS Outreach. Shirley has worked with individuals affected by HIV since 1985. Rick completed his social work internship with BAO and joined the staff in January 1994. Both are committed to providing quality services to everyone affected by this epidemic.

BAO provides both psychological services and assistance with the activities of daily living. We continue to address unmet needs and obtain access to and/or develop resources to meet those needs. In 1993 a small "meals on wheels" program was developed. Limited financial assistance for long term care was started. Since our beginning in 1985, the agency has directly served 599 men, women and children. Over 280 individuals and their loved ones were provided services last year. Sixty-four percent (64.1%) of direct financial assistance was paid for housing and utilities to maintain individuals in their own environment. Psychosocial assessment begins the development of an individualized client service plan. Follow-up is ongoing to ensure that clients receive needed services.

The questions that we most often hear regarding our services are:

What services are available for someone who has just tested positive?

POST TEST EDUCATION: A discussion of topics such as status disclosure, risk reduction, test result interpretation, and safer sex techniques.

PROFESSIONAL COUNSELING: Provided by professional staff or through referral.

SUPPORT GROUPS: Weekly meetings for people with HIV, family and friends, those who have lost someone to AIDS and women with HIV. In addition, Positive Attitudes meets monthly providing dinner and a guest speaker on a current HIV-related topic of interest to the community.

THE BUDDY PROGRAM: A trained BAO volunteer paired with a client to provide emotional support and serve as a resource person.

AIDS HELPLINE: The Helpline is answered Monday through Friday 9 a.m. to 10 p.m. by individuals trained to provide emotional support and to answer questions about HIV/AIDS, area services, resources and testing.

PEER SUPPORT CENTER: People in need of peer support will find a comfortable, safe environment at BAO to access information and meet other people coping with HIV.

How can BAO help me if I get sick and must quit my job or can't pay my bills?

EMERGENCY HOUSING ASSISTANCE: Available to clients who have exhausted other resources to help meet the costs of housing, utilities, medications, medical care, dental care, transportation, sitters and other daily living needs.

CLIENT RESOURCE CENTER: Items donated to BAO including food, clothing, medical supplies, medical equipment and household goods are made available to people living with HIV.

PRACTICAL SUPPORT PROGRAM: Volunteers provide support such as assistance with grocery shopping, house cleaning, delivery of medications and other activities to help someone through an emergency situation.

AIDS CARE TEAMS: Teams of volunteers from local churches help people with daily living needs such as grocery shopping and housekeeping and provide encouragement on an ongoing basis.

What other services does BAO provide for people living with HIV?

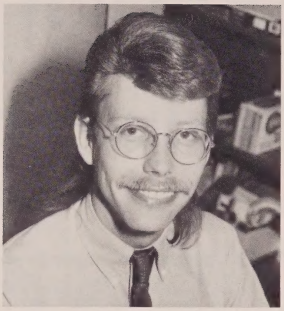
TRANSPORTATION: BAO volunteers provide transportation to medical and other appointments for clients unable to obtain other means of travel.

MOVING: BAO offers pick-up and delivery of donated furniture or other items.

MEALS: Nutritionally balanced meals are delivered to clients who meet situational criteria.

HIV/AIDS LIBRARY: BAO maintains a large selection of current information in the form of books, video tapes, recent articles, newsletters from around the country etc. on topics of interest to people living with HIV which are available for review.

Educational Programs



Bob Axelton

Bob Axelton, Education Coordinator, came to BAO in 1991 from Anniston. It was there that he gained national recognition as a pioneer to be championed in the fight against HIV/AIDS and public fear, discrimination and ignorance. In 1990 he was able to open the nation's first rural HIV outpatient clinic. Many people throughout the region know Bob as a steadfast advocate for people with HIV. He himself has had the disease for 11 years. Come by our offices to discuss any educational needs you, your church, school or organization may have. We're sure you will come away inspired and with a program tailored to meet your needs.

Birmingham AIDS Outreach is committed to reducing the spread of HIV in the Jefferson County community through aggressive and innovative programs. Current prevention programs include the BAR and PARK OUTREACH projects. These two programs are designed to assess participants knowledge and attitudes about HIV and AIDS; to increase awareness about the disease; to assist participants in assessing their personal risk for acquiring HIV; to provide a flexible assortment of alternatives to high-risk behaviors; to reinforce behavior change and to encourage prevention advocacy among the population.

BAO also offers basic AIDS education directed at the general public. Our SPEAKERS BUREAU reaches an average of 1,500 people per month. Classes are taught in such places as colleges, universities, high schools, social and fraternal organizations and churches. People living with HIV are often asked to address audiences which aides in the dissemination of accurate information and also serves to empower them, thus allowing them to regain some of the control they have lost to the disease. Their perspectives on 'real life' as it relates to HIV and AIDS is extremely valuable and presents the public with the opportunity to hear first hand what HIV is really like for them.

The BAO HELPLINE is much more than an information and referral service. This program gives callers the freedom to discuss sometimes very personal information with someone anonymously. This is often all that is needed; a kind and compassionate ear.

Education and prevention programs offer the best hope of stopping the spread of AIDS. In an attempt to reduce duplication of services and programs, BAO's education staff attends regular meetings of area HIV/AIDS Educators. Working relationships with area school boards, professionals and other agencies assures that the educational programs of BAO are culturally sensitive, fact based and available to all who need them. Further,in October of each year, BAO presents a workshop at the State Symposium. This is a conference for all state HIV/AIDS service providers.

ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

Volunteers

Pam Jones, Coordinator

1993 Volunteer Summary:

In the agency's efforts to provide a compassionate response to people living with HIV/AIDS, volunteers played a pivotal role in 1993. Even though the department underwent a transition period in identifying a full-time Coordinator, volunteers were as active in 1993 if not more so than in previous years. Their participation enabled the agency to meet its goals outlined in the 1993 Strategic Plan and also make some accomplishments beyond the stated goals and objectives. The principal reason volunteers are attracted to BAO is because they can take a leadership role in the fight against AIDS.

BAO utilizes volunteers in every aspect of its operations. The volunteer opportunities are categorized as standard, special events and special needs. The standard opportunities include: the Buddy Program, Practical Support Team, Speaker's Bureau, Transportation, Moving, AIDS 101 Planning, Positive Attitudes, Office Support and the Newsletter. Special Events are usually fundraisers such as the WALK, ONE NIGHT STAND UP, the Art Auction, etc. Special needs are support situations which are unique to individual clients, such as a client who needs a volunteer to care for pets while they are hospitalized or experiencing an illness.

Volunteers played an essential role in serving clients and in general operations. The following highlights some of their contributions in various support areas.

Fundraising:

One Night Stand Up: Volunteers led the effort in directing this special event which generated more than $130,000. Their efforts not only raised significant funding for BAO and other CBO's, but also helped to promote public awareness and generate interest in others to volunteer. More than fifty volunteers were involved in this event.

Walk: The Walk was another volunteer directed success. Twenty-one people volunteered on the steering committee and one-hundred and twenty seven participated in the overall production process. The Walk generated $108,000.

Art Auction: Twelve people served on the Art Auction steering committee and more than thirty people volunteered on the day of the event. The Art Auction generated over $10,000 in revenue.

McCraes: During the Thanksgiving and Christmas Holidays, McCraes Department Store offered BAO the opportunity to sell ornaments at its Western Hills and Century Plaza locations. More than Thirty volunteers worked the booths which raised $2,100.

Standard Opportunities:

Volunteers continued to participate in the standard areas at a constant rate. One area of popular interest is the Buddy Program. This area draws the greatest attention because it allows the volunteer to have an ongoing and direct role with a client. The area of greatest need continues to be the transportation program.

Other:

Another volunteer success story was the Holiday Outreach effort. Fifteen members of the Junior League joined with Adrian Daniels and Judy Bridgers to coordinate the holiday gift box project. More than 200 gift boxes and bags were distributed to area clients and their families. The response from the community was tremendous as volunteers wrapped boxes, solicited items, made donations and delivered the finished product to the clients.

The Junior League also sponsored the agency's holiday party. The League provided food, invitations and entertainment. More than 150 clients, friends and volunteers were in attendance.

Students from area colleges and universities continue to volunteer at BAO. Students have worked in every department, with most of their energy directed to office support. Students have committed to five hours per week and have made a major contribution.

The community has continued to show interest in the volunteer training even when they cannot volunteer. In 1993 112 people attended the training. A similar trend of interest is evident in 1994 as 31 people attended the first training of the year. Volunteers conduct the training as well as help with the location of sites and material preparation.

ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

1993 Volunteers

Races Box
Dwayne Brewer
Judy Bridgers
Dr. Bill Bridgers
Shannon Brier
Marcia Britt
Terry Brock
Ann Brown
Garry Brown
Elaine Bryan
Becky Bryant
Lyn Buchanan
Todd Burdine
Bob Burns
Tara Burr
Rob Butler
Robin Bynum-Pate
Katherine Cabaniss
Steve Calvert
Roy Campbell
Linda Cargal
Jamie Carpenter
Mark Carroll
Judi Catlett
Dalton Chandler
Steven Chappell
Anne Chateau
Marcus Childrey
Kelly Christian
Mari Ellen Clayton
Susan Clayton
Teresa Coker
Charles Collins
Mary Conley
Susan Connor
Jan Conway
Shelia Cook
Shirley Cooper
Shawn Copeland
Margaret Cothran
Claud Cotten
Cathy Cotten
Tina Council
Linda Cordisco
Rickey Courtland
Billy Cox
Amy George Cox
Cathryn Cross
Harry Cutler
Nick Daconick
Dale Dalbey
Jennifer Damon
Adrain Daniels
Alan Davis
Billy Davis
Mary Joyce Davis
Rick Davis
Don Decker
William Decker
Sister Virginia Delaney
Bill Dempsey
Dewayne Dent
Tina DiMonte
Martha Dinan
Mary Donald
Rebecca Dossett
John Douglas
Rachel Doughty
Simon Drummond
Susan Dukes
Tim Dunlap
Rebecca Dunn
Robert Durham
Karen Edwards
Glenda Elliott
Geraldine Ellis
Paul Ellis
Randall Elmore
Elizabeth Emory
Myrt Ethridge
Greg Eurick
Lydia Evans
Phillip Evatt
Paula Fancher
Fran Farris
Harry Farris
Danny Feltman
Jane Felton
Elizabeth Ferguson
Sean Fernelly
David Ferris
Rick Finn
Mary Jo Fisher
Robbie Fort
Brook Franklin
Mary Beth Fraser
Cathy Friedman
Paul Friedman
Angie Frost
John Frye
Marla Fuller
Melinda Furniss
Dan Gainey
Barbara Galloway
Larry Galloway
Ricky Gardner
Lee Gaston
Rachel Gaudel
Linda Geiss
Jessica Germany
Julie Kay Gibbs
Buzzy Gibson
Claris Gibson
Shannon Gibson
Heather Gillespy
Robert Gillespie
Cherry Gilliland
Steve Gilmer
Kathy Glover
Daniel Glover
Joy Godsey
Polly Goines
Mike Golden
Thomas Golden
Lynne Goldsmith
Melissa Goldstein
Myrna Goldstein
Beth Goodwin
Elizabeth Goodwin
Jeffery Gordan
Terri Graser
Lisa Greathouse
Tobin Greene
Bob Greenlee
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Katherine Griffis
Susan Groseclose
Teresa Gross
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Carrie Johnson
E.J. Johnson
George Johnson
Sarah Johnson
Joseph Johnson
Mary Johnson
Tracy Johnson
Lorri Johnston
Scott Johnston
Connie Jones
Sylvester Jones
Warren Jones
Samuel Jones
David Jones
Elliott Jones
Pamela Jones
Leria Lowe Jordan
Jennifer Jordan
Jo Jovings
Caitlin Keirman
Allen Kelly
Bret Kelly
Mary Loe Kevorkian
Cindy Kimbrough
Kyle Kirkwood
Tommy Kitchens
Linda Klein
Carl Klindt
Anne Knight
Karl Korendil
Liz Lehman
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Nancy Laack
Ellen Lamar
Shirley Lambert
Stacy Lane
Doug Langley
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Susan Lapidus
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Amy McNeer-Tucker
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Raymond Parker
Greg Pence
Susan Pennington
Mark Perlman
Helen Perry
Kim Peters
Richard Peterson
Debbie Petito
Tim Pfander
Chirs Pfitzer
Selton Phillips
Diane Pigot
Frank Pigot
Susanna Porter
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Melinda Powers
Jim Powerzanas
Linda Presley
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Drew Pritchett
Marian Pugh
Benjamin Putman
Jill Radwin
Tony Ravizee
Linda Reese
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Victor Warren
Guy Watson
Edward Weaver
Bobby Webster
Katherine Weed
Frank Wegent
Genie Wehling
Jill Weingarten
Timothy Welch
Peggy Werdehoff
James Wharton
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Jim Woolley
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Thom Worrell
Tawanna Wright
Elizabeth Yates
Mary Margaret Yeilding
Robert Youmans
Ralph Young
Robert Young
Tracy Zeigler
Kimberly Zeilinski

The individuals listed above have completed a volunteer application with BAO, have completed volunteer training or have reported specific hours as volunteers during 1993. BAO wishes to acknowledge those other individuals who participate in and support the programs and services at BAO but who are not listed above.

ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

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ONE NIGHT STAND UP '94

BIRMINGHAM AIDS OUTREACH

May 7, 1994 • VIP RECEPTION - 7:00 PM • GALA - 8:00 PM

B.A.O. BIRMINGHAM AIDS OUTREACH

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BIRMINGHAM,
ALABAMA 35255
PHONE: (205) 322-4197
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May 7th, 1994

Dear Supporters,

On behalf of Birmingham AIDS Outreach, I am pleased to welcome you to our annual "One Night Stand Up" Gala. This event provides us with a unique opportunity to say thank you to the hundreds of supporters who make the work that we do possible. The funds raised through this event will be used to continue our programs and services to people affected by this epidemic.

With your help, Birmingham AIDS Outreach will continue to provide financial, educational, and emotional support to persons living with HIV and AIDS. In 1993, $164,079.00 in emergency financial assistance was distributed to people with AIDS. Our current active case load of 236 clients continues to grow. The need for education continues and becomes more complex as the challenge of the epidemic expands.

Thank you for "Standing Up" with Birmingham AIDS Outreach to send a message of support and concern to the thousand of individuals who are living with this disease everyday. There is no limit to what can be achieved if we continue to work together.

Sincerely,

Sam Thompson
Executive Director

Marcia Ball, Jazz Artist

- Long and Tall
- Female Jerry Lee Lewis
- Boogie Woogie Queen
- A gifted pianist in the New Orleans R & B tradition

Born and raised in Vinton, Louisiana, of Cajun descent, Ball polished her talents in the musical mecca of Austin, Texas. Influences include the sounds of piano masters Fats Domino, Professor Longhair and Dr. John, and the blues singing of Irma Thomas.

Ball explains what ignited her fire at age 5: "My grandmother played—she was a ragtime boogie-woogie player—and had a lot of sheet music, old Tin Pan Alley music and kind of cocktail music."

At the same time Ball was aware, via the airwaves, of the magic brewing down in the big city.

"Growing up in that Lousiana-Texas border area, I listened to a lot of soul music and blues on the radio, a lot of Fats Domino," she said. "As I got older, I played more and learned about New Orleans piano players, Professor Longhair and Smiley Lewis."

The 6-foot-tall Ball has mastered the art of crossing her long legs in front of a piano and assuming the airs of a boogie-woogie barrelhouse queen. Exhibiting her own version of Jerry Lee Lewis antics on stage, Ball shakes, moves and explodes behind the keyboards. And then, to counter the tension, she'll deliver a soulfully full slow number a la Bonnie Raitt.

ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

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ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

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Joy Godsey
Ronne & Donald Hess
Eric Hunter, Ph.D.
Samuel W. Jackson & Carolyn L. Duncan
Bill Jenkins
Ray Jordan
Susan & Bill Lapidus, M.D.
Ann & George McMillan, Jr.
Max Michael, M.D.
Cindy Owen
Patrick Packer
James W. Rye
Michael Saag, M.D.
Dorothy Shaw
James D. Sokol
Alan K. Zeigler

ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

In-Kind Donors

A Social Affair
Affordable Sound and Lights
Alabama Art Supply
Alabama Crown
Alabama School of Fine Arts
Alabama School of Fine Arts Foundation
Bruce Ayers
B A Framers in Mountain Brook
Bagel Factory
Baker & Sons Dairy
Marsha Ball
Bill Johnson Designs
Birmingham Children's Theater
Birmingham Coca-Cola
Birmingham Festival Theater
Bombay Cafe
Boutwell Auditorium
Buchanan's Club
Buffalo Rock Bottling Company/Pepsi
City of Birmingham
Richie Cook
Coussiens
Curtain Call, Inc.
Devoe Paint Comapny
El Palacio
Encore Productions
Gabriel's Cafe
Godsey Design Associates
Golden Flake
Golden Temple Natural Grocery
Great American Tent Company
Greg's Cookies
Hancock's Fabrics
Kerry Hayden
Heartstrings
Holiday Inn—Redmont—City Centre Hotel
I Dolci
Interiorscapes, Inc.
J.C. Penney
Jefferson County
Johnny Ray's BBQ
Klingler's European Bakery
Kontos Produce Comapny
Kopping-Out Printing, Inc.
Lou's Pub
Magic Bagel & Deli
McGuire Contracting
Miller Lite
Mitchell's Formal Wear
Mrs. Winners
Nancy Nall
NCAP/United Way
New Era Promotions
OT's
Ousler's Sandwiches
Paper Works, Inc.
Park Lane Flowers
Peanut Depot
Pizza Hut
Readus Carpet & Cleaning Service
Phillip Rouss
Royal Cup Coffee
Tom Satterfield
Sharp Carpet Company
Shipley's Do-Nuts
LaDonna Smith
Son Ray Sportswear
Stream of Conciousness Koffiehuis
Subway
Subzone
The Galleria
The Mill
The Quest Club
The Terrace Cafe/Birmingham Museum of Art
Tracy's
Tutwiler Hotel
University of Alabama in Birmingham
Frances Verstandig
Vestavia High School Art Students
Village Pizza
Wall Street Deli
Warren Partnership

Tablescapes

Maurine Abney
The Arrangement Florist
At Your Service
Backstage Florist & Gifts
Jim Barron
Bill Johnson Floral Designs
Michael Brogan
Colours—Flower & Art
Maleah Dearman
Hoover Florist
Lamar Jeffries
Le Marche aux Fleurs
Maralyn Wilson Gallery
Martin's Flowers
Mark McCrary
Mountain Brook Flower Shop
Parisian
Rich's
Ritz Florist
Peggy Roberts
Patricia Russell
Silkwood, Inc.
Pam Spradling
Studio By The Tracks
Bart Terry
Sandy Tilt
Vestavia High School Art Students
Michael Woolley

Steering Committee

Jeff Barton, Art Display Co-Chair
Tim Blanton, Gala Co-Chair
Garry Brown, Gala Co-Chair
Bob Burns, Event Finance Chair
Rob Butler, Logistics Chair
Linda Cargal, Art Display Co-Chair
Claud Cotten, Beverages Chair
Billy Cox, Event Honorary Co-Chair
Adrian Daniels, Event Honorary Co-Chair
Tina DiMonte, Corporate Sales Co-Chair
Myrt Etheridge, Decorations Co-Chair
Joy Godsey, Event Administrator
Bill Jenkins, Host Committee Co-Chair
Warren Jones, Graphics Co-Chair
Ellen Lamar, Ad Sales Co-Chair
Jeb Lawson, Ticket Sales Chair
Ann McMillan, Event Production Chair
Kathy McGuire, Catering Chair
Sara Nall, Education Committee Chair
Wally Nall, III, Corporate Sales Co-Chair
Barry Norris, Volunteer Committee Co-Chair
Joanne Rouss, Decorations Co-Chair
Annette Ruff, Entertainment Co-Chair
Melinda Sconyers, Public Realations Chair
Brian Smith, Graphics Co-Chair
Jim Sokol, Host Committee Co-Chair
Sam Thompson, Executive Director, BAO
Bingham Vance, Volunteer Committee Co-Chair
Linda Warren, Hospitality Committee Co-Chair
Norma Warren, Hospitality Committee Co-Chair
Jill Wheeler, Entertainment Co-Chair
Rachael Doughty, Ad Sales Co-Chair

ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

Event Volunteers

Alexander, Rene
Allison, George
Anderson, Gloria
Arrasmith, Ann
Axelton, Bob
Barnes, Shawn
Barr, Thomas
Barrow, Paul
Barton, Jeff
Belk, Daniel
Bemis, Carla
Bennett, Mikul
Bevis, Mike
Blanton, Tim
Boyd, Rebecca
Brooks, Sharron
Brown, Jeannie
Brown, Katy
Brumstead, Margaret
Burke, Christopher
Burns, Bob
Butler, Rob
Byrd, Bruce
Callaway, Tracey
Cargal, Linda
Carr, Rebecca
Carr, Tom
Carter, Chris
Cash, Dan
Cather, Patrick
Chen, Jennifer
Christie, Chris
Cochran, Stephen
Collins, Charles
Conn, Glen
Cotten, Claud
Council, Tina
Cox, Billy
Cronan, Keith
Croney, Larry
Crowe, Jon
Curren, Todd
Dalbey, Dale
Daniels, Adrian
Davis, Sue Sue
Davis, David
Desforges, Susan
DiClemente, Dr. Ralph
DiMonte, Tina
Dodd, Sister
Doughty, Rachael
Dunkin, Mike
Elsas, Ellen
Ennis, Kimberly
Ethridge, Angie
Ethridge, Myrt
Evans, David
Fiore, Paula
Fulton, Angelia
Garry, Brown
Garza, June
Gibbons, Heather
Gibbs, Miquel
Gillespie, Robert
Godsey, Joy
Green, Janice
Griggs, Mark
Gunnell, Terry
Gunter, Van
Haralson, Danny
Haralson, Vicki
Harkless, Kenneth
Harris, Meredith
Harris, Mike
Harrison, Jonathan E.
Hess, Donald
Hipp, Jean
Hogg, Sara
Howell, Lee
Hudson, Randall
Hunter, Alan
Hunter, Dr. Eric
Irwin, Marcia
Irwin, Marsha
Jackson, Mollie
Jenkins, Bill
Johnson, Greg
Johnson, Margaret
Jones, Warren
Jordan, Leria Lowe
Kennedy, Carrie
Kennedy, Ted
Kunzman, Eileen
Lamar, Ellen
Langley, Doug
Lapidus, Susan
Lawson, Jeb
Lee, Carlos
Leesburg, Judy
Lehman, Liz
Letchman, Cynthia
Logan, Amy
Logan, Dan
Lyons, Sherry
Manderson, Landy
Manning, Marilee
Martin, Lois
Maske, Glen
McCluney, Judd
McCulloh, Caye
McCulloh, Cole
McElheny, Allsion
McGuire, Kathy
McMillan, Ann
Michael, Sara
Mim, Bernard
Nail, Scott
Nall, Nancy
Nall, Sara
Nall, Wally, III
Neel, Jim
Nicks, Carol
Nicks, Johnny
Norris, Barry
Norton, Allison
O'Beirne, Rosie
O'Brien, Mike
Packer, Patrick
Padaline, Zach
Page, Jay
Parsons, Michael
Partin, Heather
Pleasant, Pat
Posey, Adrian
Prosch, Ceil
Raiford, Robert
Reese, Mattie
Rhodes, Zane
Roberts, Kirk
Robinson, Larry
Rose, Vernon
Rouss, Joanne
Rouss, Keith
Ruff, Annette
Salmon, Leigh
Sampson, Julie
Schmidt, Melanie
Sconyers, Melinda
Seto, Lauren
Share, Natan
Sheridan, Carolyn
Sherrill, John
Shimizu, Jeff
Sims, Brad
Slone, Stephanie
Smith, Regina
Sokol, Jim
Stagner, Darlene
Stuckey, Ted
Symms, Barbara
Syms, Jay
Thomas, Judy
Thompson, Koby
Thompson, Sandra
Tipton, Tim
Trouhton, Alex
Turner, Amy
Updike, Matt
Vance, Bingham
Vaughn, Brian
Walker, Susan
Warren, Linda
Warren, Mackey
Warren, Norma
Watson, Chris
Weeks, Donna
Weeks, Steve
Weinstein, Jason
Welborn, Barbara
Welborn, Mike
West, Randy
Wheeler, Jill
White, Brian
White, Christie
Whitley, Joe
Wise, Jim
Wright, Karen
York, Jeff

1993 Budget Highlights

BALANCE SHEET/DECEMBER 31, 1993 WITH COMPARATIVE TOTALS FOR 1992

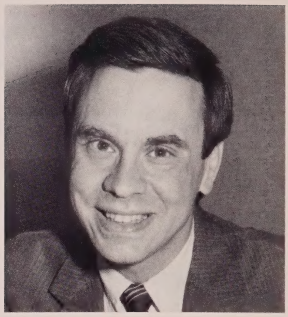
	Current Funds		Property & Equipment	Total All Funds	
ASSETS	Unrestricted	Restricted	Fund	1993	1992
Cash	$ 133,404	$ —	$ —	$ 133,404	$ 65,356
Accounts receivable (note 2)	—	—	—	—	9,145
Deposits	4,655	—	—	4,655	4,655
Property and equipment, net (notes 3,5 and 6)	—	—	335,475	335,475	333,470
Total assets	$ 138,059	$ —	$ 335,475	$ 473,534	$ 412,626
LIABILITIES AND FUND BALANCES					
Note payable (note 4)	$ —	$ —	$ 2,058	$ 2,058	$ 1,536
Accounts payable	—	—	—	—	6,032
Accrued expenses	5,156	—	—	5,156	1,481
Total current liabilities	5,156	—	2,058	7,214	9,049
Note payable (note 4)	—	—	68,058	66,058	68,288
Total liabilities	5,156	—	68,116	73,272	77,337
Contingencies (note 6)					
Fund balances (note 6)	132,903	—	267,359	400,262	335,289
Total liabilities and fund balances	$ 138,059	$ —	$ 335,475	$ 473,534	$ 412,626

STATEMENT OF SUPPORT, REVENUE, EXPENSES AND CHANGES IN FUND BALANCES FOR THE YEAR ENDED DECEMBER 31, 1993 WITH COMPARATIVE TOTALS FOR 1992

	Current Funds		Property & Equipment	Total All Funds	
SUPPORT AND REVENUE	Unrestricted	Restricted	Fund	1992	1991
Contributions	$ 233,435	$ 53,805	$ —	$ 287,240	$ 104,707
Grants (note 5)	88,750	27,247	—	115,997	179,845
Special events	254,007	—	—	254,007	262,918
Rental income	9,413	—	—	9,413	48,949
Other	5,550	—	—	5,550	2,275
Total support and revenue	591,155	81,052	—	672,207	598,694
EXPENSES					
Program services	411,611	81,052	6,486	499,149	411,849
Support services	103,762	—	4,323	108,085	95,560
Total expenses	515,373	81,052	10,809	607,234	507,409
Excess support and revenue over (under) expenses	75,782	—	(10,809)	64,973	91,285
Transfer of equipment	(12,814)	—	12,814	—	—
Transfer of principal payments	(1,708)	—	1,708	—	—
Beginning fund balances	71,643	—	263,646	335,289	244,004
Fund Balances, end of year	$ 132,903	$ —	$ 267,359	$ 400,262	$ 335,289

See accompanying notes to financial statements

1993 Budget Highlights



Barry Norris, Treasurer

STATEMENT OF FUNCTIONAL EXPENSES FOR THE YEAR ENDED DECEMBER 31, 1993 WITH COMPARATIVE TOTALS FOR 1992

	Program Services		Support Services		Total All Funds	
	Client Services	Education	Management and General	Fundraising	1993	1992
Advertising	$ 1,607	3,213	268	268	5,356	306
Cleaning services	1,644	822	5,343	411	8,220	6,047
Conferences	2,373	2,373	—	—	4,746	7,054
Consultants	—	—	—	—	—	5,948
Disbursements to CBOs	29,520	—	—	—	29,520	47,499
Educational supplies	—	12,569	—	—	12,569	46,087
Employee benefits	9,390	5,892	2,209	921	18,412	10,253
Financial assistance	161,286	—	—	—	161,286	86,325
Food bank	1,471	—	—	—	1,471	—
Insurance	3,695	3,695	411	411	8,212	6,807
Interest	6,914	—	—	—	6,914	7,764
Legal and professional	2,447	2,375	2,015	360	7,197	15,391
Nutrition	—	5,350	—	—	5,350	—
Office supplies	3,483	2,090	697	697	6,967	4,934
Other	2,918	2,832	1,716	1,116	8,582	7,855
Payroll taxes	4,567	2,865	1,074	448	8,954	8,436
Postage	4,381	5,476	548	548	10,953	11,832
Printing	1,110	1,077	653	424	3,264	11,809
Production for special events	31,465	31,465	—	41,954	104,884	53,683
Products	—	—	—	1,019	1,019	9,482
Rent	—	—	—	—	—	5,512
Repairs and maintenance	13,960	13,960	1,551	1,551	31,022	18,858
Salaries	57,763	36,244	13,591	5,663	113,261	85,324
Security	499	249	1,621	125	2,494	1,551
Telephone	4,580	4,580	509	509	10,178	11,169
Travel	2,089	2,089	232	232	4,642	5,158
Utilities	4,189	2,096	13,621	1,046	20,952	23,081
	351,351	141,312	46,059	57,703	596,425	498,165
Depreciation	4,540	1,946	3,783	540	10,809	9,244
Total expenses	$355,891	$ 143,258	$ 49,842	$ 58,243	$ 607,234	$ 507,409

See accompanying notes to financial statements

1993 BAO Budget Highlights

NOTES TO FINANCIAL STATEMENT

(1) Summary of Significant Accounting Policies

(a) Organization

Birmingham AIDS Outreach, Inc. (BAO) was incorporated in July 1985 under the laws of the State of Alabama.

BAO is a non-profit organization formed to serve people affected by the Human Immunodeficiency Virus (HIV). Primary emphasis areas related to this mission include client service, education, networking, and resource development.

(b) Basis of presentation

BAO records its activities on the accrual basis, recognizing contributions when received, grant revenue when earned, and expenses as incurred.

(c) Fund Accounting

To ensure observance of certain constraints and restrictions placed on the use of resources, the accounts are maintained in accordance with the principles of fund accounting. Accordingly, resources for various purposes are classified for accounting and reporting purposes into funds that are in accordance with the nature and purpose of such funds. The assets, liabilities and fund balances are reported in the following self-balancing fund groups:

- Current funds include unrestricted and restricted resources available for support of operations.
- Plant funds include expendable resources restricted for land, buildings and equipment.

(d) Property and equipment

Property and equipment are recorded at cost to the Organization or at market value at the time of donation. Depreciation is based on the straight-line method over the estimated useful lives of the assets acquired. Repairs and maintenance are expensed as incurred.

(e) Contributions

Contributions are considered available for unrestricted use unless specifically restricted by donor.

(f) Income taxes

The Agency is a tax exempt entity under Section 501 (c) (3) of the Internal Revenue Code. Accordingly, no provision for income taxes is reflected in the accompanying statements.

(g) Functional expenses

The Agency allocates its expenses on a functional basis among its varied programs. Expenses that can be identified with a specific program are allocated directly according to their natural expenditure classification. Other expenses that are common to several functions are allocated by various statistical methods.

(h) Donated materials and services

Volunteers, business firms, and others contribute substantial amounts of materials and services toward the fulfillment of the Organization's projects. These donations have not been recognized in the financial statements due to the fact there is no objective basis available to measure the value of the donated materials and services.

(2) Accounts Receivable

Accounts receivable consists of the following:

	1993	1992
Celebrate, Inc.	$ —	$ 5,838
Art Auction proceeds	—	2,880
Rent	—	427
	$ —	$ 9,145

(3) Property and equipment

Property and equipment consists of the following:

	1993	1992
Land	$ 54,000	$ 54,000
Buildings (see note 6)	281,082	281,082
Equipment	24,129	11,315
Software	3,269	3,269
	362,480	349,666
Less accumulated depreciation	27,005	16,196
	$ 335,475	$ 333,470

NOTES TO FINANCIAL STATEMENT

(4) Note Payable

The note represents a mortgage note obligation to an individual:

	1993	1992
Mortgage note, monthly payments of $675 including interest at 9%, secured by real property	$ 68,116	$ 69,124
Less current portion	2,058	1,536
	$ 66,058	$ 68,288

Maturity requirements on this debt are summarized below:

1994	2,058
1995	2,251
1996	2,462
1997	2,693
1998	2,946
1999 and thereafter	55,706
	$68,116

(5) Grants

BAO received the following grants during the year ended December 31, 1993:

	1993	1992
City of Birmingham	$ 71,250	$ 119,315
State of Alabama	23,005	23,005
Other	19,242	25,025
Corporate grants	2,500	12,500
	$ 115,997	$ 179,845

(6) Contingencies

The warranty deed for the building donated by the City of Birmingham contains a clause requiring BAO to revert title to the building back to the City if BAO ceases to exist as a nonprofit, charitable organization or fails to comply with certain provisions and requirements.

(7) Pension Plan

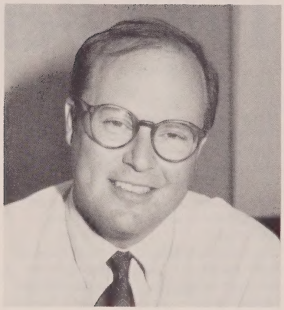
The Organization purchases an annuity for all full-time employees who have been employed for six months. Currently the contribution is equal to 4 per cent of each employee's salary.

The cost charged to expense under this plan was $2,974 and $3,033 for the years ended December 31, 1993 and 1992, respectively.

(8) Lease Agreements

BAO rents space to several tenants. At December 31, 1993, income expected to be generated under non-cancelable lease agreements amounted to $3,680 to be received in the year ending December 31, 1994.

1993 Donors



Bob Burns, Resource Development

$100 to $250

AIDS Task Force of Alabama
Livy B. Abele
Gregory Adams
L.L. Adamson
Birmingham Area Chamber of Commerce
Josephine & Brandt Ayers
Bagby Elevator Company, Inc.
N. Carlton Baker
Dawn Bailey
Patricia Beard
Elizabeth & J.D. Bell
Matina Bevis
William Berry
Honey Bigelow
E.J. Bissell
David Blake
Tim Blanton
Lynn Bledsoe
Allison Bliss
I. Sheldon Blumenfield
Margret Brennan
Elizabeth Bridewell
Marilyn Briles
Emily Brown
Garry Brown
Alley Bulka
Michael Bulgaris
Bulgaris Heating & Air
Mary Burge
Joan Burns
Sybil Burton
Daniel & Rebecca Campbell
Keith Carmichael
Pam Carter
Mary Casey
Aleen Carter
Judith Catlett
Bart Cavender
Robert & Susan Chapman
Stephen Chazen
John Claypool
Susan Clayton
Holt Cloud
David Coker, II
Charles Collins, Jr.
Anne Connors
Constangy, Brooks & Smith
Jan Conway
Olinda Cook
Shelia Cook
Elizabeth Cooke
Sondra Cory
Brooks Cotten
Claud Cotten, III
Sallie Creel
Betty Crocker
Peggy Daley
Martin Damsky
Daughters of Charity
David K. & Company, Inc.
Alan Davis
Mary Davis
T.W. DeCair
Susan & Tommy Deramus
Joel Dillard
Laura Douglas
Mary Duke
James Dunlap
Lynn Duvall
Lois Eady
Ed's Pet World
Glenda Elliott
David Farris
Elizabeth Ferguson
Murray & Marion Fintel
C.E. Foshee, Jr.
Allan Francis
Tyese C. Frazier
Burton Freed
John Fuller
Roger Gaith
Stacy Gibbs
Claris Gibson
Roger L. Gill, D.M.D.
William Paul Glass
Barbara Goggans
Golden Apple Associates
Gerry Goldstein
Milton Goldstein
Richard Goldstein
Jeffery Gordon
M. M. Gorrie
Terri Grasser
Gravlee Fitness & Body
Judy Grimmett
Steve Haeberle
James Hall, Jr., M.D.
Doyle Haymon
Jack & Linda Hays
Aaron Hemnr
John Herring
Samuel D. Herring
Mark Herron
Kathy Heyer
Donald Hicks
Highland Music Shop
Catherine & William Hiles
Warren Hooks
John Howze
Frank Hrabe
David Hruska
Kristie Hudson
Beth & Patrick Hughes
Dr. Eric Hunter
Elton Hurst
Lucie Iannotti
Margi Ingram
Instant Sign Center
Interim Healthcare
Judy Irving
Paul Irwin
Dudley Jackson
Jefferson County AIDS in Minorities
Jefferson Iron & Metal
Jeff Johnson
J.L. Squared, Inc.
Michael Jones
Phyllis Jones
Jones Office Supply
Altha Jordan
William & Leria Jordan
Randy Judd
Jim Kamplain
Charles E. Kellum
Carol Key
Mary Jane Kilgore
Jerry Kirby
Tommy Kitchens
Knesseth Israel
Annie Knight
Marty Knight
Byron Kopman
Janis Lachut
L'Amicale Women's Club
Yves Le & Josh Kiser Lain
Jerome Lapidus
Maxine Lapidus
Matthew & Amy Sanders Levey
Kathy Livingston
Glenn Lockett
Anthony Longobardi
Jerry Lorant
Gabriella Lynn
Willa Madden
Market Research Management
Lois Martin
Gordan Maxwell
Merchandise Vending
Kelly McCormack
James McGill
James McKee
C. McKenzie
William McNair
Tracy Metcalf
Louis & Cathy Mezrano
Micheal Gibson Company
Dr. Mark Middlebrooks
Stewart Miller
Mindus Recycling
Barbara Minor
Ira & Ann Mitchell
Marchina Mitchell
Margret H. Moody
Carol Moore
Pam Moore
Elizabeth Morrison
Jane Morrow
Charlotte Murdock
N.A.L.C. Auxiliary
Benny Nash
Katherine Nelson
Stanley Nelson
New South Federal
O3 Inc.
Kala & James O'Brien
Mildred O'Byrne
Darryl Oden
Gregory Odrezin
Omicron Omega Chapter, AKA
Our Lady of Sorrows
Kenneth Parker
Michele Parr
David & Margo Parrish
Gary Pate
Gayle Pelham
Joan P. Pepper
Anne S. Peyton
Jeff Pierson, Jr.
Porter, White & Yardley
Melinda Powers
Shelton Price
Mary Pritchett
Ralf W. & Frances Drennen Quinn
Jim Raper
Lois Ray
Sheldon Reid
Lisa Rhodes
Susan Robinson
David Romanoff
Julie Royer
Annette Ruff
Ann Russell
Fredric Rutledge
James Rye, Jr.
Lewis Rylee
Katherine Samford
Sankey 2, Inc.
Sardis Baptist Church
Karen Scherer
Schlinkert Sports Associates
Lorlee & John Schoenlein
John Seagle
Joseph & Mei Ching Seeds
Raymond Schackleford
Janet Sharpe
Shearson Lehman Brothers
Ryan Shipman
Richard Siegal
Laurence Signaigo
David A. Simmons
Robert Sims
Fern Singer
Kim Singleton
George Smith
Smith & Hardwick
James Sokol
Scott Spain
Derrick Spellman
David & Natalie Sperling
St. Thomas Episcopal
St. Barnabus Youth Ministries
Teresa Stano
Gypsy Stephens
T. Charles Steward
Mary Stewart
Dana Streety
Mark Strength
Elizabeth Sutton
Barbara Taylor
Evan Thayer
Phil & Jane Timberlake
Don Todd
Tom Williams Automotive
Lisha Townsend
Bethay Tricia
Trocadero, Inc.
Albert Tully
Temple Tutwiler
Mimi Tynes
UAB Health Services Foundation
Valley United Methodist Church
James Venable, III
Linda Verin
Karen Waldrep
Tommie Waldrop
Marion Walker
Paul Weir, M.D.
E.P. Whatley
David White
Shelia White
James H. White, III
Tondaleria Williams
Smith Williams, III
Joanne Willis
Bob Wilson
Michael Wilson
Robert Wilson
Tawanna Wright
Barbara Zarzaur

$250 - $500

ACIPCO
Anne H. Bailey
Cliff & Anne Bennet
Ken Botsford
Marilyn Briles
Jim Brunstad
Bob Burns
Joan W. Burns
Catherine & William Cabaniss
Charles Caldwell, III
Cathy Calvert
Eli Capilouto
Beverly Chace
Coca-Cola Bottling Co.
Communication Concepts
Billy Cox
Rochelle Crow
Joseph Daniel
James & Natalie Davis
William A. & Dana B. Davis
Billy Davis
Kenneth Davis, Jr.
Rev. Ron & Eleanor Delbene
Debbie Diehl
Lois Eady
Fredrick Elsas

1993 Donors (continued)

Charles & Kimberly Fagan
H.W. & Francis Farris
Rick Fennell
Freeman Stained Glass
Ronald Garza
Allan Goldstein
Jody Gottlieb, Ph.D.
Terri Grasser
R. Rex. Harris, M.D.
Robert Haughton
John Scott Hawkins
Pamela Hebert
Gary Hill
Blaine Humphrey
Jilbere Hair Salon, Inc.
Johnson, Rast & Hayes
Belinda Jones
David Lee Jones
Carrie King
Josh Kiser
Martha Klinner
Murray Knight
Kay Knowlton
Karl Phouka Korendil
Dr. Willaim & Susan Lapidus
Stanton Lee, Jr.
Timothy J. Lennox
Gary Little
Mayer Electric
Marion Merrell Dow, Inc.
Cheryl McDonald
Suzanne Michalek
Micheal Moody
Sara & Wally Nall, III
Dewey Narkates
Cynthia Nelms
Jimmy Nicholson
Park Lane Flowers
Greg Pence & Pat Rippetoe
Jay Phillips
Pizitz Management Group
Terry Proctor
Jason Quarles
James Ray
Lois Ray
James Rimel, III
Russell Rivera
Edward Robbins
Carol Rosenstiel
Perry Schwartz
Sherman International
Sims Corporation
David Smalley
William Smith
St. Peter's Catholic Church
Stasia Tapley
Ted & Debby Thomas
W. Duer Thompson
Timothy Tipton
Rick Turner
Susan Vaughn
Lolita M. Virciglio
Katherine Weed
Eugenia Wehling
James Wharton
David White
Harry Wingfield
Michael & Lauren Woolley

$500 - $1000

Dawn Bailey
Louise Beard
Bill's Club
Birmingham News/Post Herald
Dr. William & Judy Bridgers
Brookwood Baptist Church
Bob Burns
James Pat Cather
Ray Clarke
Cowin Equipment Co., Inc.
Dewberry Home Health
Jerry Dinatale, Jr.
Burton & Rebecca Dunn
Randall Elmore
Ernst & Young
Paul & Cathy Friedman
Michael Harris
Gary Hill
Hoffman LaRoche
Earline Howell
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ONE NIGHT STAND UP
BIRMINGHAM AIDS OUTREACH

AIDS Awareness '94

Each year, as part of "One Night Stand Up", Birmingham AIDS Outreach sponsors a special educational activity to raise HIV/AIDS awareness and understanding among local high school students. As the number of young people infected with HIV continues to increase, the need to identify new and more effective ways to educate teenagers grows. Many young people have joined forces with BAO during the Walk and through projects sponsored by Youth Leadership Forum. These young people continue to tell us that more information is needed.

On April 9th, with the help of local educators and community leaders, BAO hosted a day of discussion and demonstration for dozens of area teenagers. Six individual sessions were held to demonstrate the variety of programs and presentations that are available through BAO for use in their schools, at club meetings and in other youth forums. The response was tremendous and the feedback has already begun to shape how Birmingham AIDS Outreach will educate youth in the coming year.

In addition, BAO has identified a group of young people who have agreed to serve as a Youth Advisory Committee. By staying in touch with what area youth feel is most important and what formats are most effective, we can make meaningful strides toward giving young people the skills to avoid becoming infected with this virus.

Listed below are the individuals and businesses who helped make "AIDS Awareness '94" the successful beginning of that process.

Mrs. Sara Nall—One Night Stand Up, Education Chair

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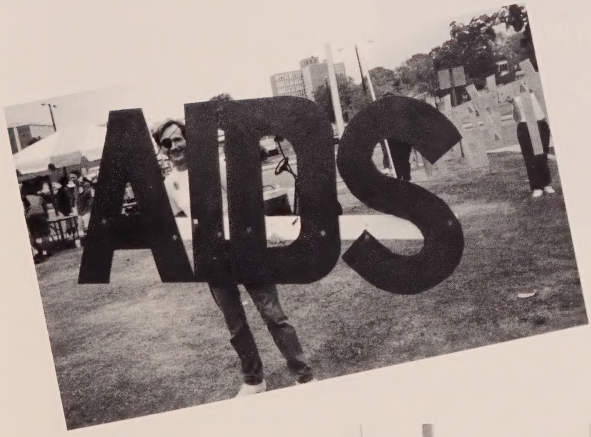
The Alabama AIDS Walk

For All Walks of Life
Sunday, October 23rd, 1994

The Alabama AIDS Walk has, in its two year history, become the largest single demonstration of concern and support of it's kind in Alabama. In 1993 over 5000 individuals participated in one of the most successful fund raising efforts ever conducted by Birmingham AIDS Outreach. With the help of more than 150 volunteers, and the support of individuals and teams from all over the state, over $108,000 dollars was raised for AIDS organizations across Alabama. Special recognition was given to the two largest teams, BellSouth and St. Vincent's . Gerry Mitchell was, for the second year in a row, awarded the title of most successful individual fundraiser.

The enthusiasm demonstrated during the '93 walk encourages us to set our goals even higher for 1994. Mark your calendar now for this special day of activity.Encourage your friends and family to attend the walk with you. Together we can continue to send an important message of support to people with AIDS in Alabama. Together we can let the people of Alabama know that we will not stop until there is a cure.

If you are interested in getting more involved in the planning of the 1994 Alabama AIDS Walk, please contact the BAO business office at 322-0757.



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and under their
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none shall make
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Micah 4: 3-4

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JOHN DONNE

{ **in support of 'one night stand up'.** }

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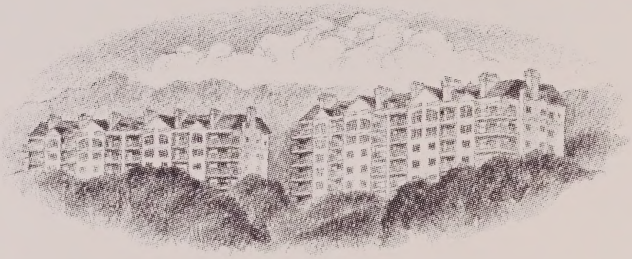

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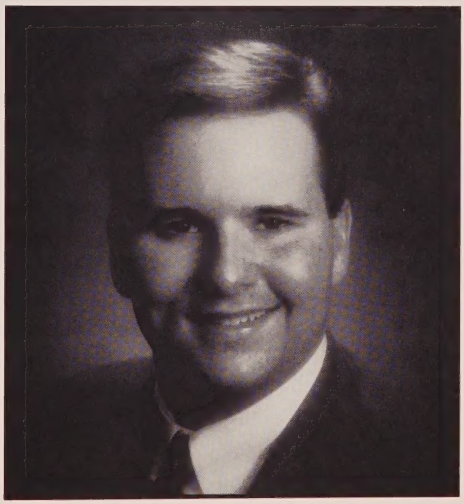

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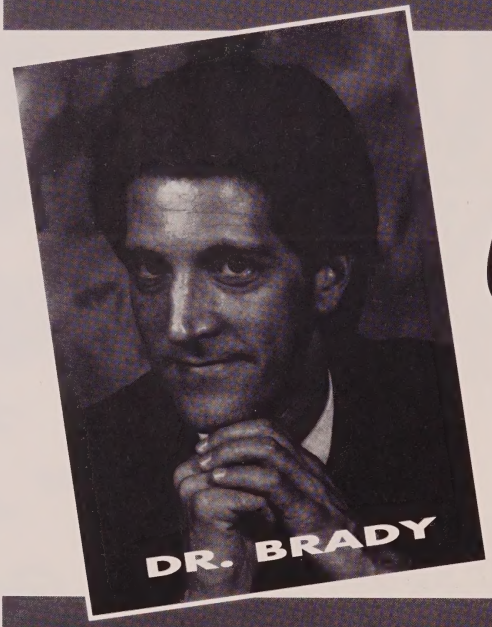

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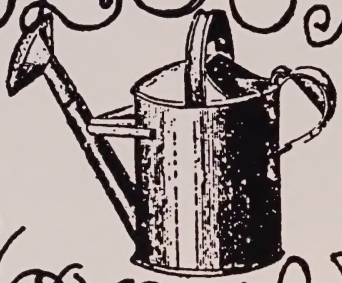

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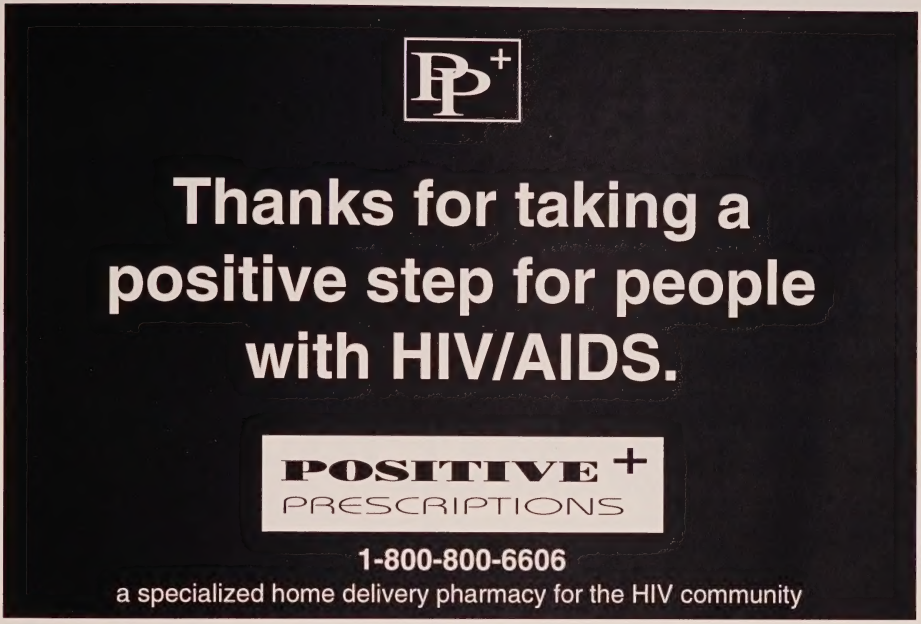
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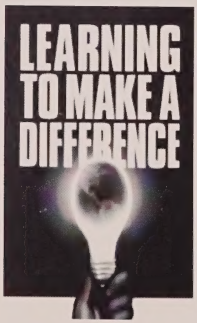

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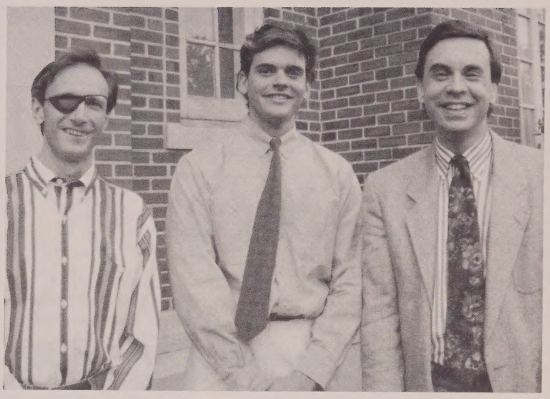

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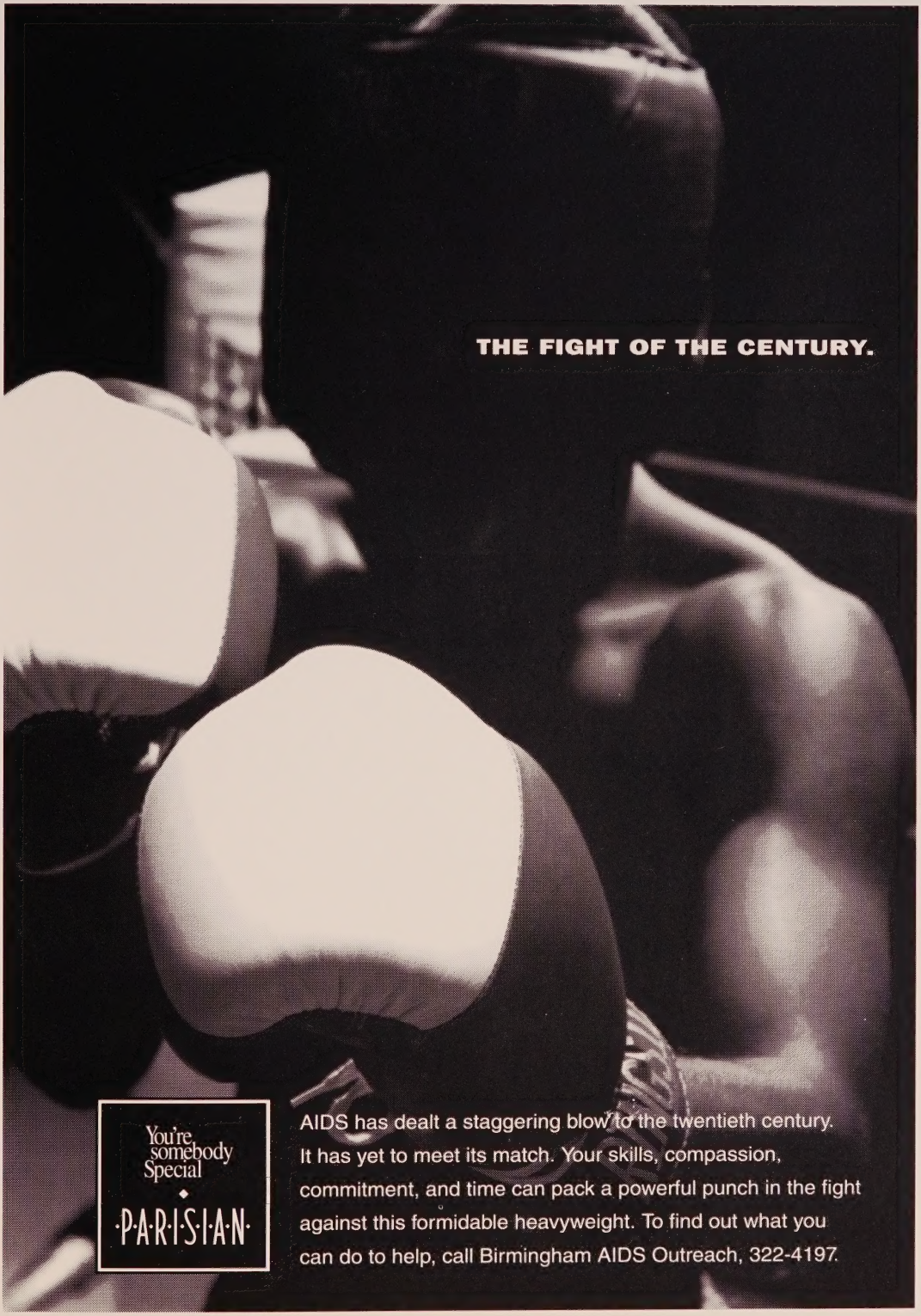
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A Note from the Producer

As a television medical reporter, I have covered the AIDS epidemic for more than a decade. My work has resulted in invitations to speak to thousands of young people. Their bold questions and desperate need for information led me to produce several resources, including In Our Own Words: Teens and AIDS, Risky Times: How to be AIDS-Smart and Stay Healthy and Sex Education in America: AIDS and Adolescence.

I have been fortunate to meet and work with many people with HIV and AIDS. They have been my teachers and my friends. In telling their stories, they speak honestly, from the heart.

It is my hope that young people who see In Our Own Words: Teens and AIDS will be more willing to acknowledge the threat of HIV and have the information and skills they need to make and act on healthy decisions.

Jeanne Blake

What People Are Saying About In Our Own Words: Teens and AIDS

"In Our Own Words: Teens and AIDS is right on target for young people...dramatic enough to hold their attention, realistic enough to be absolutely believable. The medical information is sound and right on target."

Dr. Timothy Johnson-Medical Editor, ABC News

"The video clearly lets young people know, 'You have the power to prevent HIV/AIDS from happening to you.' Hopefully, many young people will be given the opportunity to see the video."

Marion Howard-Author, *Postponing Sexual Involvment*

"In Our Own Words: Teens and AIDS is a tremendous achievement. The program manages to deliver lifesaving prevention information to teens in a way that is clear and powerful, yet not condescending. The video is also a moving tribute to five young people with AIDS."

Gregory Adams-National Minority AIDS Council

"In Our Own Words: Teens and AIDS is a powerful video. It can help students realize that other young people like themselves have contracted HIV. An important component in a larger HIV prevention program for adolescents."

Doug Kirby, Research Director-ETR Associates

Design/Production-Momentum & Dickinson Associates

The Printing of this brochure is made possible by Summit Press

Media Works, Inc.
P.O. Box 15597 Kenmore Station Boston, MA 02215
800.600.5779

In Our Own Words: Teens and AIDS

a 20 Minute Video

"When I was 15, I found out that the guy who was my second sex partner had HIV, so I got tested. When the doctor told me I tested positive, my life — as I knew it — ended."

Kerry, Host of *In Our Own Words: Teens and AIDS*

Teens and AIDS

"When I was diagnosed, I didn't know what to think...and I had all those questions that came into my mind. Am I going to die? When? How? How am I going to tell my family? How are they going to react? "

AIDS is one of the greatest public health threats of the century, and young people are among the most vulnerable. Public health experts report that the rate of HIV infection among teens is increasing at an alarming rate. Surveys show that many young people continue to put themselves at risk for HIV through unprotected sex. As they face the challenge of adolescence, young people need and deserve to have information and skills that can help them stay healthy.

In Our Own Words: Teens and AIDS is a new 20 minute video in which five young people with HIV speak out about AIDS. Each of the young people was infected as a teenager through unprotected sex. They address denial, living with HIV, alcohol and its link to HIV, postponing sexual activity, condom use and the importance of making healthy decisions.

Kerry Carson, the 21 year-old host of the video died five weeks after completing her work on the project. Pedro Zamora, a cast member of MTV's *The Real World,* who died in November of 1994, is also profiled in the video.

In Our Own Words: Teens and AIDS is a resource for the classroom and the home. A complete Educator's Discussion Guide accompanies each video. The video is recommended for grades seven and higher.

In Our Own Words: Teens and AIDS was written and produced by television medical reporter Jeanne Blake, the President of Media Works, Inc., a non-profit production company which produces written and visual materials on public health issues. The video was funded by major grants from the Ford Foundation and Blue Cross and Blue Shield of Massachusetts.

Additional Resources Available from Media Works

Risky Times: How To Be AIDS Smart and Be Healthy

Risky Times has been critically acclaimed and approved for use in the health curricula of high schools across the country. The American Library Association named *Risky Times* to the list of "Best Books for the Young Reader" and the list of "Best Books for the Reluctant Reader." The book includes chapters on the biology of HIV, making healthy decisions, drugs and alcohol and their affect on risky behavior, the effectiveness of latex condoms, treatments and vaccines and discrimination. Available in English and Spanish. Books include a free Parent's Guide. Recommended for grades six and higher.

Sex Education in America: AIDS and Adolescence

Sex Education in America: AIDS and Adolescence is an hour-long television documentary that aired nationally on PBS stations. The documentary features conversations with four young people living with HIV who address why teenagers persist with risky behavior, why young people and their parents have a difficult time discussing issues surrounding sexuality and how education can help break down barriers of denial.

"I wish as a teenager, I'd valued myself more. If I had, I would have postponed having sex. I would have talked with my partner about whether we were ready to have sex. If you can't talk with your partner ... maybe you're not ready."

Pricing For Media Works Resources

To Order Your Copies of:

1 *In Our Own Words: Teens and AIDS,* The 20-minute video. Includes Educator's Discussion Guide. Price $99.00 (plus $5.00 shipping and handling.) *For orders within Massachusetts, include 5% sales tax ($4.95) or send a copy of an Exempt Certificate. Please make your checks payable to Media Works, Inc.*

2 *Risky Times: How to be AIDS-Smart and Stay Healthy,* by Jeanne Blake. This 158 page book profiles 15 young people with HIV and AIDS and offers celebrity quotes on subjects relevant to chapters including biology of HIV, treatments and vaccine, denial, drug use, condoms and discrimination. Includes a free Parent's Guide. *Risky Times* is available in Spanish, *Tiempos De Riesgo w/Parent's Guide.* Price $6.00 (add $3.00 shipping and handling.) *For orders within Massachusetts, include 5% sales tax (30 cents per book) or send a copy of an Exempt Certificate. Please make your checks payable to the Risky Times Book Project.*

3 *Sex Education in America: AIDS and Adolescence,* Media Works, Inc., 1993. This 60-minute documentary examines the threat of HIV to young people and how to best reach them with information and skills. Includes examination of five AIDS/sexuality curricula. Four of the HIV-positive young people from *In Our Own Words: Teens and AIDS* are profiled in this video. Includes interview with former Surgeon General Joycelyn Elders. Price $39.95 (plus $4.00 shipping and handling.) *For orders within Massachusetts, include 5% sales tax ($1.99) or send a copy of an Exempt Certificate. Please make your checks payable to Media Works, Inc.*

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Dear Friends:

There have been many video's produced to help in the fight for a better way to prevent the spread of AIDS in our country, **"In our Own Words: Teens and AIDS"** is certainly among the very best.

This documentary, in which teens with HIV are given the opportunity to tell their own stories directly to the viewer, is an exceptionally powerful tool for AIDS prevention and education. I was deeply moved by the way in which each of these young people came to terms with their own lives and, in addition, provided messages of hope that infection with HIV is not inevitable for teens or anyone else.

This video provides the last opportunity to see and hear from Padro Zamora, who is featured prominently in the documentary. His energy, sincerity, charm and deep compassion for all persons, makes a profound impression on the viewer. As a cast member on MTV's Real World, he reached millions of young people and showed them how living with AIDS can be done with courage and grace. While he is no longer with us, his message of hope for America's youth will now live on through this project.

I hope you will consider using this unique resource as part of any AIDS prevention or awareness program for all ages, but especially for young people. I'm confident you will be pleased with its content, quality, and impact to take one more step towards the end of this nightmare called AIDS.

Sincerely,

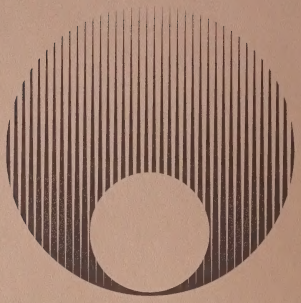
Rev. Kenneth T. South
Executive Director

110 Maryland Avenue, N.E. Suite 504 Washington, D.C. 20002
VOICE: 202-546-0807 FACSIMILE: 202-546-5103

NATIONAL PEDIATRIC HIV RESOURCE CENTER
SUMMARY OF ACTIVITIES

NPHRC 1990-1991

NATIONAL PEDIATRIC HIV RESOURCE CENTER
SUMMARY OF ACTIVITIES
1990-1991



NATIONAL PEDIATRIC
HIV
RESOURCE CENTER

The National Pediatric HIV Resource Center

The National Pediatric HIV Resource Center (NPHRC) is a nonprofit organization that serves professionals who care for children and families with HIV infection and AIDS. Founded in 1990 the Center offers consultation, technical assistance, and training for medical, social service, and planning personnel.

NPHRC promotes family-centered, comprehensive, community-based systems of health care and is dedicated to assuring the delivery of competent, compassionate, and culturally relevant care. A central goal is to help develop a national network and infrastructure of service delivery systems which meet the needs of children, women, and families with HIV infection and AIDS.

NPHRC has quickly moved into a national leadership role in the field of pediatric and family HIV infection. A component of an internationally recognized clinical program, the Center has access to state-of-the-art treatment developments in the field of pediatric and family HIV/AIDS.

NPHRC serves organizations and professionals caring for children with HIV infection and their families through several innovative methods. The Pediatric HIV Core Curriculum — an in-depth theory and clinical training course for physicians, nurses, social workers, and other care providers — is offered on a regular basis. In addition, mini-fellowships offered at CHAP are designed to enhance providers' clinical skills. Other workshops focus on ethnic and cultural issues and on training for pediatric nurses, school nurses, and mental health professionals. Most services are free of charge.

NPHRC has established collaborative relationships with key organizations and individuals working in the area of pediatric HIV infection. Among the organizations with which it works are the pediatric HIV/AIDS demonstration projects funded by the Maternal and Child Health Bureau, the National AIDS Clearinghouse, the AIDS Clinical Trials Group, state Title V programs, and regional AIDS Education and Training Centers.

Individuals who have been instrumental in shaping the activities of NPHRC include both distinguished national experts who serve on an Advisory Committee and family members of children with HIV infection. Working groups organized by NPHRC always include family representation.

The National Pediatric HIV Resource Center is a project of UMDNJ-New Jersey Medical School and the Children's Hospital AIDS Program of Newark, New Jersey. It is funded in part by Project # BRH PRC021-01-0 from the Maternal and Child Health Bureau, HRSA, U.S. Department of Health & Human Services.

The Second Decade

The epidemic of perinatally transmitted HIV infection and AIDS has revealed the cruel reality that as a nation, we lack a health care system that provides access to compassionate care to those most in need. Two decades of working in Newark, New Jersey has taught us that health care for women and children often comes as a last priority of our health care system.

How do we galvanize people into paying attention to the war on AIDS right here at home? At a time of shrinking resources and lack of coordination on health issues, we are faced with a crisis in our communities.

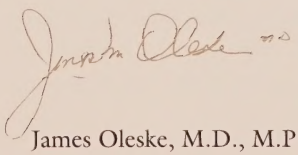
Every day at the AIDS Program of Children's Hospital, we watch children and their parents, foster parents, and grandparents struggling to cope with the impact of HIV on their lives. They must grapple with caring for their families, securing benefits and housing, providing transportation, and obtaining health care for themselves and their children. In many cases, mothers are ill themselves. All too often, grandparents are caring for both their children and grandchildren who are infected with HIV. We have also learned from families the strength of the human spirit to live and love and grow in spite of HIV disease.

We have struggled — not always successfully — to create a system of compassionate, culturally sensitive, and comprehensive health services for women, children and families with HIV/AIDS in New Jersey. While the number of children we serve has grown, painfully, from 10 in 1984 to over 400 today, we have gained experience serving children and families.

The National Pediatric HIV Resource Center was created so that we could begin to provide information to other professionals. Now in its second year of operation and with eight full-time professional staff, we have the capability to conduct education and training programs, monitor policy trends, and provide technical assistance to programs from across the country.

If we are to call attention to the health crisis in the United States and develop an effective response to it, it is essential that patients, parents, professionals, and advocates join together in partnership. Towards this end, the National Pediatric HIV Resource Center dedicates its efforts.

Mary Boland, R.N., M.S.N.



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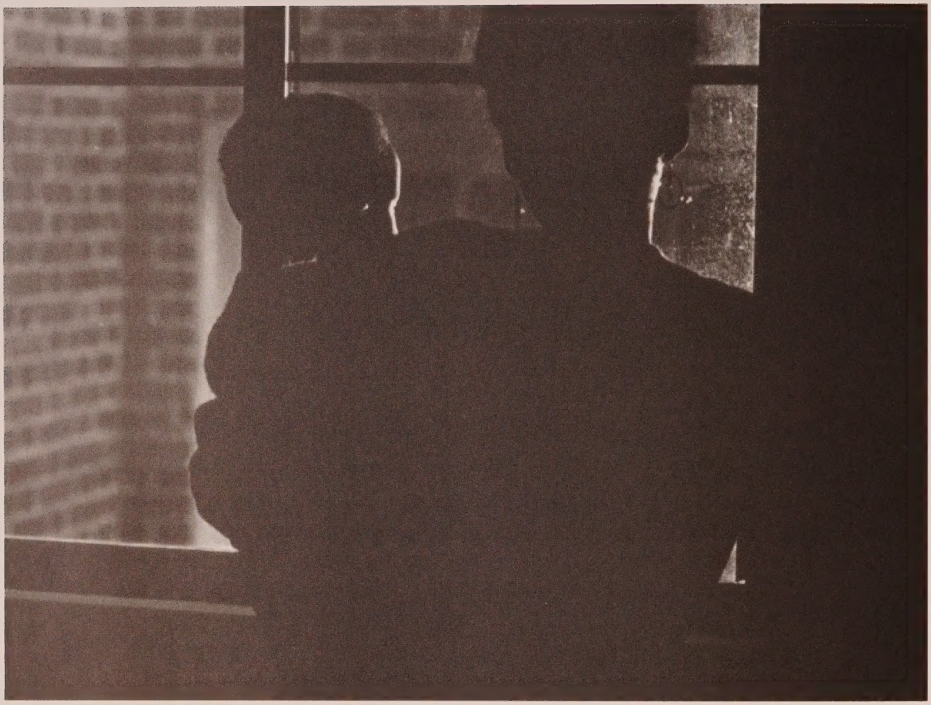
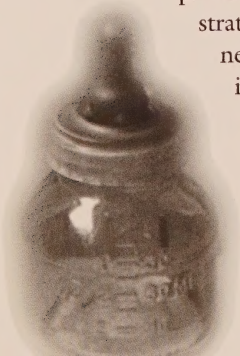


The Epidemic in Brief...

The HIV epidemic is growing rapidly among children, adolescents, and women in the United States. By the end of December, 1991, the Centers for Disease Control (CDC) had reported 3,471 children with AIDS, the end stage of HIV disease; of these, 1,621 were still alive (CDC, HIV/AIDS Surveillance Report, January 1992). Another 789 cases of AIDS had been reported among adolescents aged 13 through 19, and 21,225 cases had been reported among women aged 20 and over. Taken together, children, youth, and women accounted for over 12% of all AIDS cases reported in the country. Cases of pediatric AIDS had been reported from 47 states, the District of Columbia, Puerto Rico, and the Virgin Islands. Indeed, of the 95 metropolitan areas in the country with populations exceeding one-half million, 91 had reported cases of pediatric AIDS by September, 1991. Twenty-one percent of the total number of pediatric AIDS cases and 27% of the cases among women were reported during the single year ending in December, 1991.

Because the onset of AIDS generally occurs several years after infection with HIV, these figures greatly understate the total number of children, adolescents, and women in the country with HIV infection. No reliable counts of people with HIV infection are available; the CDC has noted that just 22 states, which account for only about 20% of the reported AIDS cases in the country, mandate the reporting of HIV infection. However, a recent study published in the Journal of the American Medical Association, based upon newborn seroprevalence data from 38 states in 1988 through 1990, has estimated that 1,800 infants with HIV infection are born each year in the United States. Other estimates have placed the total number of children with HIV infection in the country in the range of 10,000 to 20,000 and the total number of women of childbearing age with HIV infection at approximately 80,000. Growing rates of adolescent pregnancies and sexually transmitted diseases raise concerns that the HIV epidemic is gaining force in the adolescent population as well. A recent study of Job Corps applicants in the United States confirms that there are growing rates of HIV infection among socially and educationally disadvantaged youth and that these rates were nearly as high in females as in males.

Children with HIV disease need ongoing care that is family-centered, community-based, comprehensive and coordinated. To effectively serve families affected by HIV, the providers who care for them need access to the most current information and strategies for management, treatment, and approaches to care. Providers also need the opportunity to stay up-to-date on national policy issues which impact on service delivery locally. The National Pediatric HIV Resource Center offers a range of services responsive to providers' needs in these areas.



Services of the National Pediatric HIV Resource Center

CONSULTATION & TECHNICAL ASSISTANCE

NPHRC strives to support the development of family-centered, comprehensive, community-based systems of care for children with HIV and their families. Consultation is provided to individuals and agencies designing new programs to serve children and families with HIV, modifying existing programs to address HIV, developing community-based consortia, or developing grant proposals.

Agencies or individuals requesting consultation are asked to identify specific goals in order to facilitate access to appropriate resources and staff. Consultation activities involve discussions with appropriate staff, review of materials, assistance with needs assessment, and evaluation planning. Some consultations take place via telephone and through exchange of materials, while others involve visits between NPHRC and the consulting agency.

NPHRC has provided consultation to agencies and individuals across the United States and territories. Program staff have visited NPHRC and CHAP, with in-depth consultation and technical assistance given to selected agencies and hospitals developing and expanding HIV services to families. Specific issues addressed included financing, internal policy development, provision of medical, nursing, and counseling expertise, and other areas of program development.

Head Start Task Force

In response to growing concerns and interests in serving HIV affected children in day care and child development programs, NPHRC began a consultation process with Head Start providers in HHS Region II (New York, New Jersey, Puerto Rico, and the Virgin Islands). The Head Start program provides comprehensive education, nutrition, health, social, and other services to preschool children who are economically disadvantaged and is committed to involving parents in activities with their children. The program enjoys wide recognition for its success at limiting federal administrative costs while providing much needed high quality early childhood services for children from low-income families including children with physical and developmental handicaps.

NPHRC has identified Head Start as a model service delivery program for children with special needs and a valuable resource for children with HIV. Head Start programs around the country are, in many instances, already serving children with HIV infection or AIDS and have requested assistance regarding medical and psychosocial issues, coordinated services, and legal issues.

From left to right

Samuel Grubman, M.D.
Coordinator for Medical Education

Julia delC. Aleman, M.S.W.
Social Work Educator

Linda Rangel
Data Secretary

Sandra Y. Lewis, Psy.D.
Psychologist Educator

Mary G. Boland, R.N., M.S.N.
Director

Arthur Burlington, M.A.
Coordinator for Information Systems

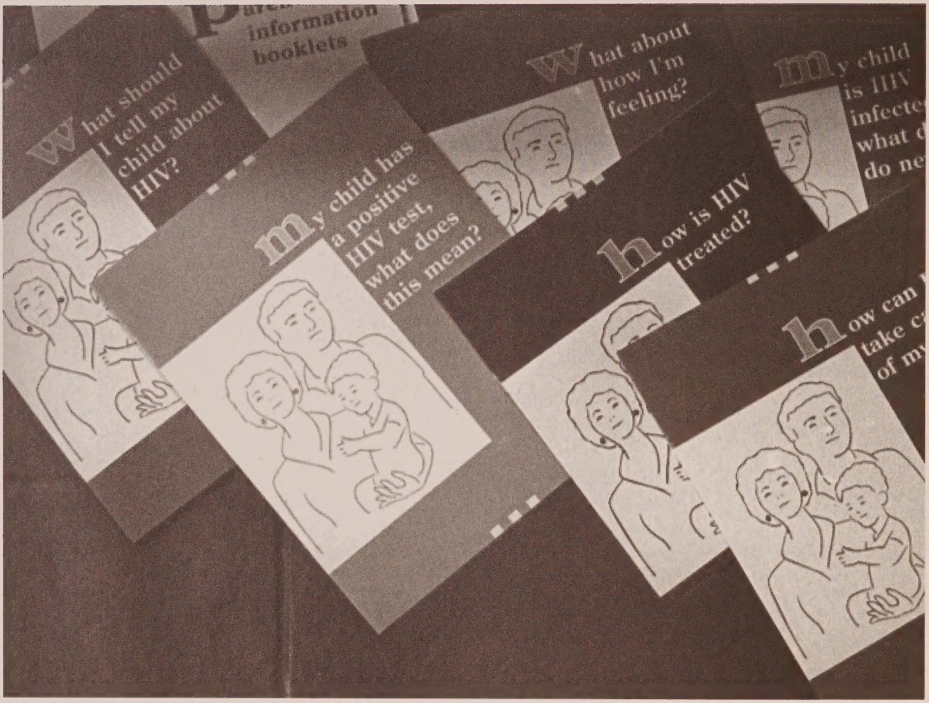
Carolyn K. Burr, R.N., M.S.
Program Coordinator

Marie L. Dargan, M.P.H.
Program Administrator

Magaly Garcia
Administrative Assistant

Kathryn Gray-Quinn
Administrative Coordinator

David Harvey, M.S.W.
Policy Analyst


information booklets
What should I tell my child about HIV?
My child has a positive HIV test, what does this mean?
What about how I'm feeling?
How is HIV treated?

Under the direction of NPHRC psychologist Sandra Lewis, Psy.D., and social work educator Julia Aleman, M.S.W., a project is underway with the Region II Head Start Resource Center to assist Head Start providers to respond to the needs of children and families affected by HIV.

A working task force of Head Start providers from Region II is consulting regularly with NPHRC staff to produce a resource guide and curriculum for Head Start programs. The materials will cover issues related to health and psychosocial concerns, ethnic and cultural issues, and developmental needs. A major emphasis of the materials will be to address staff fears and concerns regarding transmission, confidentiality, and other programmatic development issues. These materials will be disseminated to Head Start programs throughout Region II.

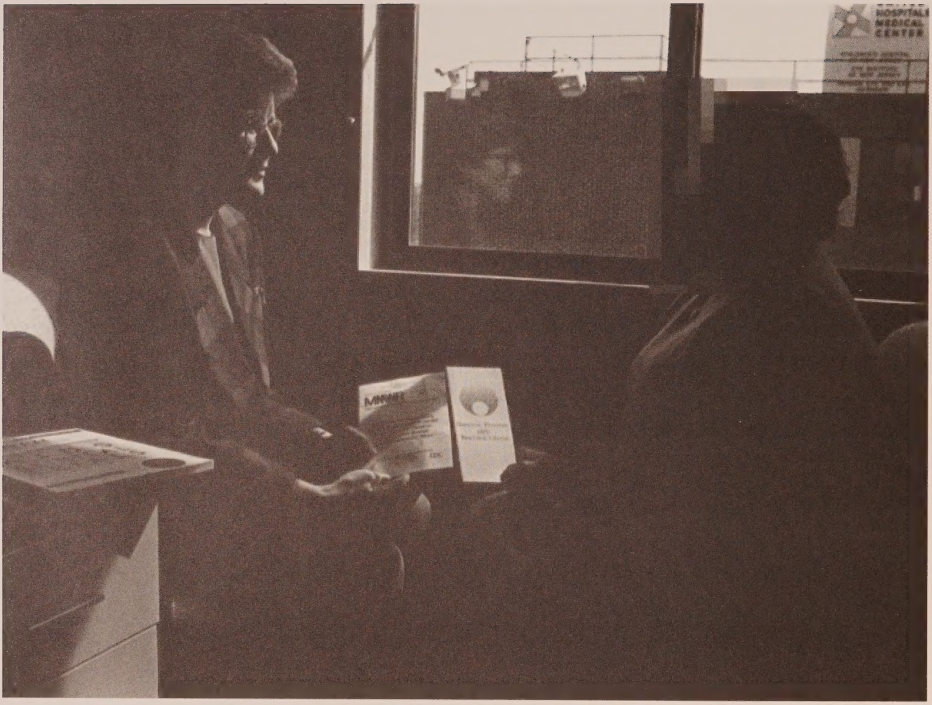
LEGAL TECHNICAL ASSISTANCE

NPHRC has offered technical assistance on legal issues facing providers caring for children with HIV infection through the law firm of Feldsman, Tucker, Leifer, Fidell & Bank in Washington, D.C. Attorneys from the firm participate in Core Curriculum and have responded to technical assistance requests from individual programs. The principal product of legal technical assistance has been the development of a manual on legal issues for pediatric HIV providers. Available in 1992, the manual covers issues such as confidentiality, informed consent, and investigational drug trials. The manual also focuses on concerns specific to the care of children, such as custody and foster care, and on liability issues facing providers developing care programs.

INFORMATION DISSEMINATION

Central to NPHRC's contribution to the field of pediatric HIV are publications disseminated by the Resource Center, as well as scholarly journal publications written by staff on current medical, clinical, and service-related practices. During 1990-1991, all NPHRC staff and individual staff of the Children's Hospital AIDS Program (CHAP) were involved in preparing manuscripts and publishing journal articles in areas related to psychosocial issues, nursing care standards, sensitivity to cultural and ethnic issues, service design systems, and treatment developments.

The Center is also committed to assisting in the development of patient and family educational materials. Materials — based on families' expressed needs — have been developed, and assistance is offered to programs developing and disseminating materials. Materials currently available have been developed in collaboration with families. Written at a 6th-7th grade reading level, the materials are available in both English and Spanish. In consultation with experts in the field, including families, NPHRC is developing guidelines to assist providers in producing materials which are culturally competent. Nearly 5,000 copies of the *Parent Information Booklets* series have been distributed to families through programs across the United States.


HOSPITAL
MEDICAL
CENTER

FORUMS ON PUBLIC POLICY AND STANDARDS OF CARE

In late 1990, NPHRC convened a Work Group, chaired by Dr. Edward Connor of CHAP and Dr. Walter Hughes of St. Jude's Children's Research Hospital in Memphis to develop guidelines for prophylaxis against *Pneumocystis carinii* pneumonia (PCP) for children with HIV. Members of the work group included pediatric HIV researchers, physicians, and nurses who attended the meeting from throughout the country. PCP is the most common serious HIV-associated opportunistic infection among children, and it was diagnosed in 39% of the 2,788 pediatric AIDS patients reported to the CDC through 1990. PCP is often the initial clinical sign of HIV infection in infants, most commonly occurring in infants 3 to 6 months of age. PCP is a serious cause of morbidity in HIV-infected children, and mortality is high. However, studies of children with cancer and adults with HIV disease have shown that PCP can be effectively prevented by giving prophylactic antibiotics to at-risk patients.

The impetus for the Work Group to develop guidelines for PCP prophylaxis for children with HIV infection was newly reported research on the correlates of PCP in infants and immune function in healthy children. The guidelines offer providers across the country a standardized approach to evaluating and monitoring children at risk for PCP. It is anticipated that the guidelines, if widely implemented, can make a significant contribution to future treatment of the currently estimated 20,000 children infected with HIV in the U.S. The guidelines were reviewed and endorsed by the U.S. Public Health Service and were published March 15, 1991 in the Centers for Disease Control's *Morbidity and Mortality Weekly Report.* They were reprinted in the April 15, 1991 edition of the *Journal of the American Medical Association.*

Policy Forum

NPHRC has played a supportive role in monitoring and providing technical assistance on the implementation of the Ryan White Comprehensive AIDS Resources Emergency Act, passed by Congress in 1990. Together with the Maternal & Child Health Bureau of HRSA, NPHRC helped sponsor a meeting with the pediatric HIV/AIDS demonstration projects on Ryan White implementation. NPHRC is involved with the development of a technical assistance plan for pediatric HIV/AIDS demonstration projects under the Ryan White legislation.

In June of 1991, NPHRC opened a Washington office staffed by David C. Harvey, M.S.W., Policy Analyst, who will monitor and analyze policy trends within Congress and federal agencies. Mr. Harvey will serve as liaison with federal government officials and provide technical assistance on the rapidly emerging funding and policy issues associated with pediatric and family HIV infection.

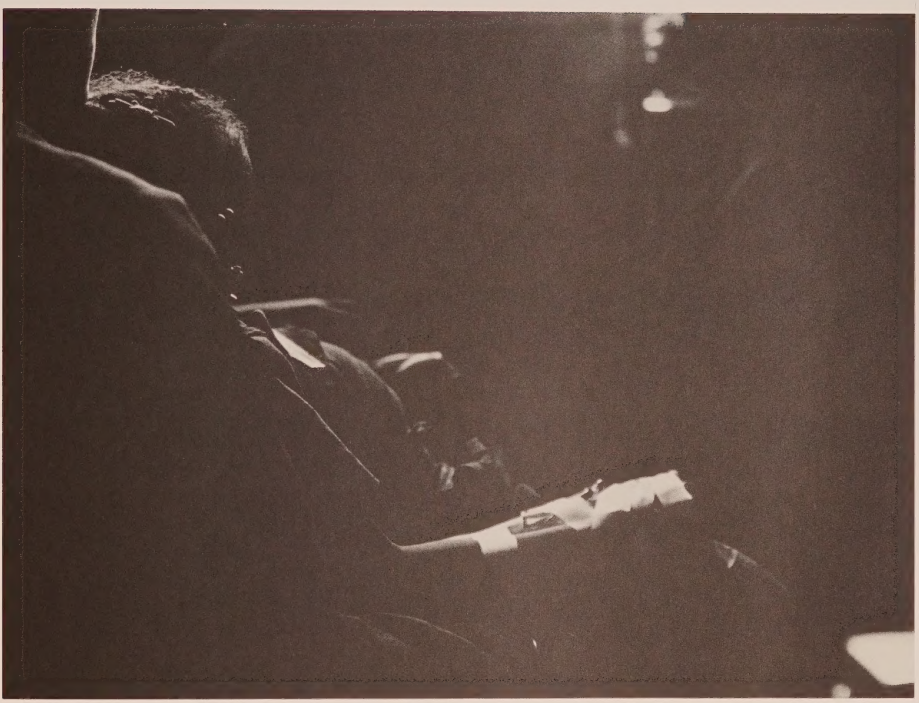
TRAINING

Ethnicity, Culture, and Families Living with HIV: A Workshop for Providers

Under the direction of psychologist educator Sandra Lewis, Psy.D., a specialist in African-American cultural and ethnic issues related to HIV disease, this workshop concentrates on information about culturally sensitive models of service. Ethnocultural sensitivity is vital to providing effective health care and social services, especially as they relate to HIV disease and AIDS. NPHRC is committed to stimulating cultural awareness and sensitivity among professionals providing care to children with HIV infection and their families.

While HIV does not discriminate in whom it can affect, approximately 85% of infected children are Black or Latino/Hispanic. The majority of these children and mothers cope with poverty, drug abuse, and involvement with multiple social service agencies. These children and families have particular and specialized service needs associated with HIV that must be delivered in a culturally sensitive manner.

Among the topics covered in the workshop is awareness of the unique ways in which Black and Latino/Hispanic families are affected by HIV and AIDS. In addition, sensitivity to the potential combined impact of poverty, minority status, and the stigma of HIV and AIDS upon children and their families is emphasized. Other issues include drug abuse and AIDS and their effect upon ethnic minority children and families, and culturally sensitive "safer sex" strategies.

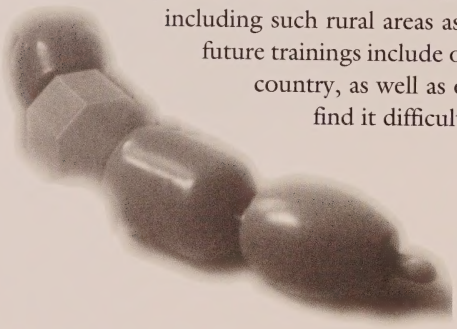


The Pediatric HIV Core Curriculum

In response to an urgent need for state-of-the-art information by service providers around the country, NPHRC developed as an educational model the Pediatric HIV Core Curriculum. This curriculum provides in-depth theory and clinical training for physicians, social workers, nurses, and other service providers caring for children and families with HIV.

The goals of the curriculum, as organized by NPHRC Coordinator Carolyn Burr, R.N., M.S., are to increase providers' expertise in the pathophysiologic and psychosocial aspects of pediatric HIV, to strengthen their competence in planning for family-focused, comprehensive, community-based care, and to enhance their skills as resource persons in their agencies and communities. The curriculum is offered over five days and is led by a multidisciplinary staff from NPHRC and the Children's Hospital AIDS Program. Topics covered in the curriculum include virology, medical management, psychological interventions, ethnic and cultural influences on care, service planning, legal issues, and other concerns.

During 1990-1991, over 100 professionals from hospitals, clinics, and community agencies throughout the country attended the curriculum. Participants included professionals from areas where services are expanding for persons with HIV, including such rural areas as upstate New York and South Carolina. Plans for future trainings include offering the program at various locations around the country, as well as offering a shorter curriculum for professionals who find it difficult to be away from their programs for five full days.



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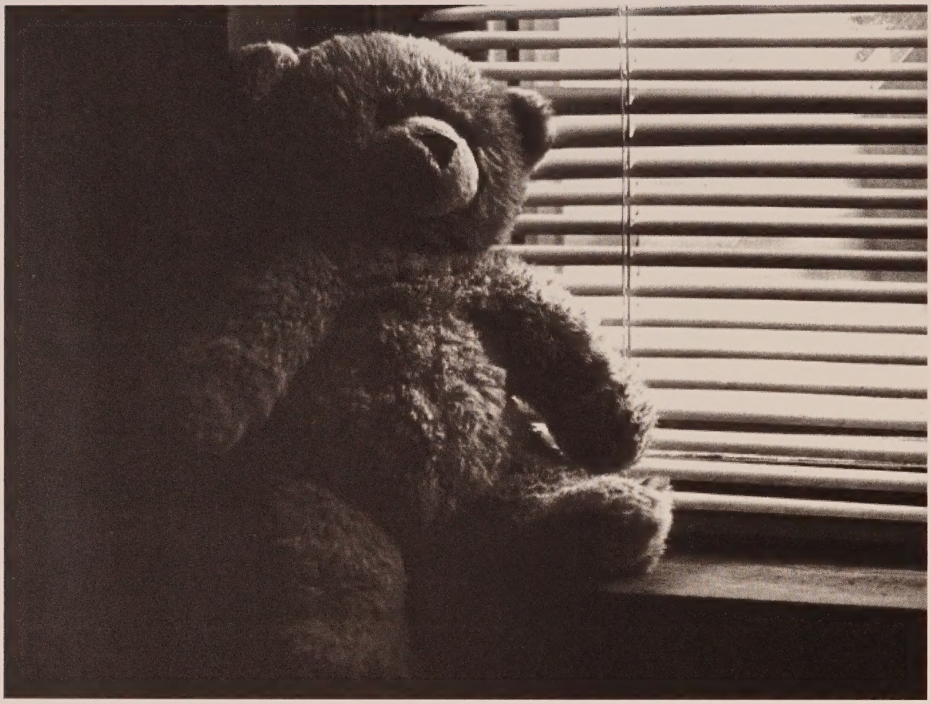


Pediatric/Perinatal Nurses Program

Many community hospitals and agencies are just beginning to confront the reality of pediatric AIDS and the specific clinical course of the disease in children. Although knowledge is advancing regarding adults with HIV disease and AIDS, there are differing clinical and medical treatment issues for pediatrics. Developmental problems coupled with a greater degree of central nervous system complications are examples of the differing course of the disease in children.

Under the direction of Nurse Educator Elaine Gross, R.N., M.S.N., this specialized day-long program is directed to nurses who work specifically with pediatric patients and in perinatal units. Many of the participants who attend this program are from hospitals where there is no specific HIV unit or expertise in HIV disease and AIDS. Introductory information is given on epidemiology, transmission, diagnosis, HIV infection in pregnant women, and psychosocial issues. In addition, immune system functions of children and medical management and treatment issues are covered. Discussion concerning infection control procedures is also presented. The program utilizes adult learning strategies to involve participants in the process and to provide an approach which deals with attitudes as well as knowledge about HIV in children. More than 700 nurses have attended over the past three years.

This year, the program was adapted as a train-the-trainer model to enable nurse educators and HIV trainers to utilize this approach to train nurses in their own communities. The target audience for this training program includes nurses from state departments of health, health and nursing consultants, as well as faculty from nursing programs at universities, AIDS Education and Training Centers, pediatric AIDS demonstration projects, hemophilia treatment centers, hospital education and training staff, and others. This program has been conducted in New Hampshire, Los Angeles, Seattle, and at the Center in Newark, New Jersey.

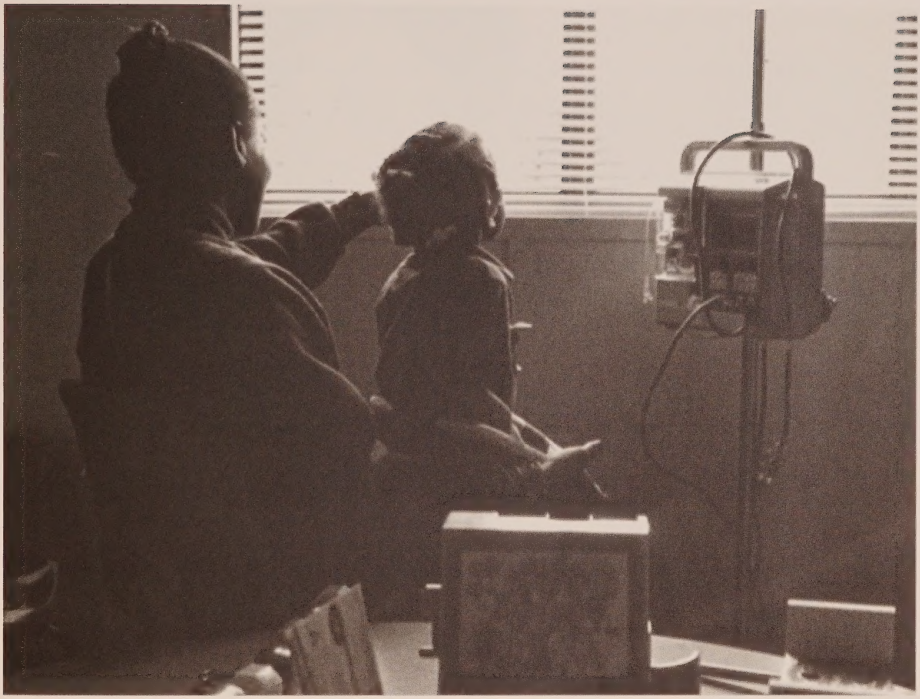
School Nurse Training Program

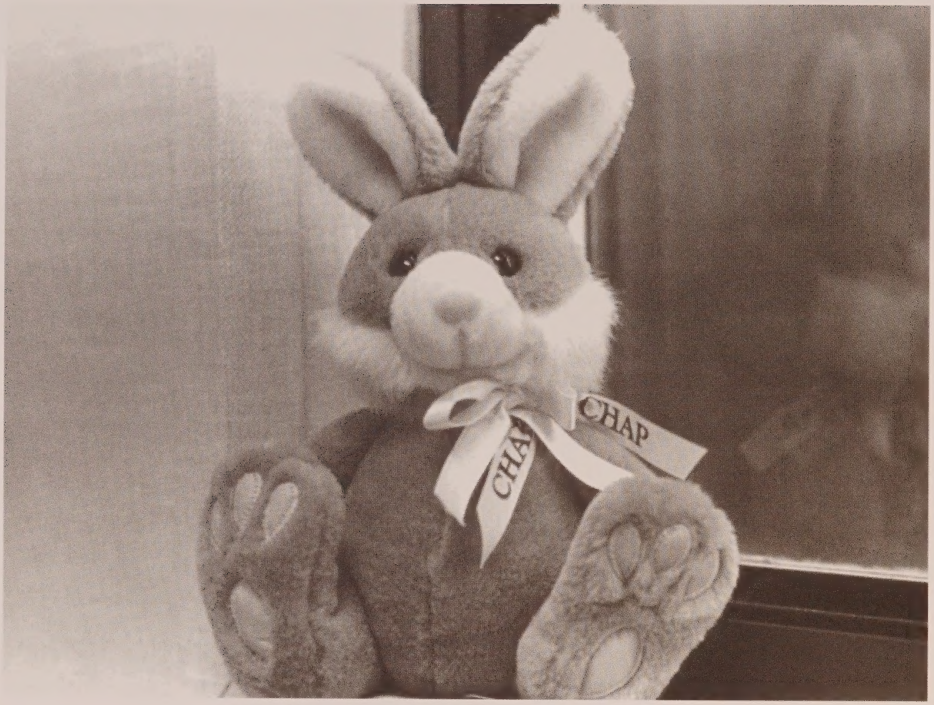
School nurses have a special role to play in caring for children with HIV who attend school. With improved medical care, early recognition of HIV infection in children, and the availability of medicines such as AZT, children with HIV infection are living longer and attending day care and school. School nurses play a pivotal role in helping children take their medications, as well as monitoring health conditions. This day-long program, also under the direction of Elaine Gross, R.N., M.S.N., provides school nurses with specific skills to promote the health of children with HIV in school, as well as addressing particular concerns around assuring confidentiality and working with teachers.

This program will be developed into a train-the-trainer program to be held at the NPHRC office in Newark, New Jersey and other locations around the country. School nurse consultants and HIV trainers from state departments of health and education and regional AIDS Education and Training Centers will be recruited to participate in this training and then offer it to nurses in their own area.

Clinical Fellowship Program

Clinical fellowships are offered to physicians, nurses, social workers, and mental health professionals who wish to gain specialized knowledge of advanced pediatric HIV treatment. Individualized programs are designed which team the fellow with a trained preceptor at CHAP who serves as a colleague and mentor. Under the direction of Samuel Grubman, M.D., Coordinator of Medical Education, and James Oleske, M.D., FXB Professor of Pediatrics, fellowships range in length from a few days to a month and provide experiences including inpatient clinical care and community-based case management.




CHAP

CLINICAL EDUCATION

To enhance its role as a national center, NPHRC is committed to the belief that in its role as an expert and specialized national training and resource center, staff must maintain clinical expertise through participation in clinical services at the Children's Hospital of New Jersey (CHAP).

Patients, families, and care providers who confront the daily challenges of living with HIV are the experts in understanding the issues at hand, and it is this direct experience that educators must learn. This commitment to patients and families pervades all of the goals and activities of NPHRC. NPHRC is committed to contributing "state-of-the-art" information to the field through training, consultation and technical assistance, information dissemination, and by serving as a forum for public discussions on policy and standards of care.

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NATIONAL PEDIATRIC
HIV
RESOURCE CENTER

The National Pediatric HIV Resource Center is a project of
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Member of the AIDS National Interfaith Network

Vol. 2, No. 4

Red Ribbon Reflections

AIDS Education and Ministry Project

Involving Alabama in compassion, education, and ministry

April/May, 1995

Defining a direction for the AIDS Education and Ministry Project

by Malcolm Marler

The purpose of the AIDS Education and Ministry Project is to teach individuals and congregations how to make a difference in the AIDS epidemic through compassion, education, and ministry development. Our primary focus is on congregations of all faiths, but we also understand the necessity to work with numerous community groups.

The AIDS Education and Ministry Project is based in the UAB 1917 Clinic, a leading AIDS research and treatment center. But, this Project also has to be transportable, going into cities, small towns, and rural areas throughout Alabama.

I believe we can be effective in accomplishing our mission by focusing on three areas. The first of these is through *program development*. We will offer quality model programs that congregations, communities, and individuals can utilize without "reinventing the wheel" when they want to get involved. An example of this has been the development of AIDS Care Teams (ACT), a realistic and practical way for small groups of people to make a difference. In order for an ACT to be successful, we offer quality training, leader support/supervision, and continuing education for participants.

A second focus area is helping leaders develop more effective *educational programs* for the communities or congregations where they serve. Preventive education (including sexuality education) is critical in this battle. The real tragedy in this epidemic is we know how to prevent the spread of this disease, but have failed to teach prevention effectively.

Finally, the third way we can accomplish our mission is in the development of an *Alabama AIDS Interfaith Network*. This communication network will help churches, synagogues, AIDS service organizations, educational institutions, and other community groups to collaborate on projects together. Everything we attempt in AIDS education or ministry should include the question, "Who can help us accomplish our task more efficiently in our community?"

Malcolm Marler is the Director of the AIDS Education and Ministry Project at the University of Alabama at Birmingham's 1917 Clinic.

Red Ribbon Reflections

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Mailing list additions/changes: Please send name, address, day and night phone numbers to the above address.

Volunteer Training May 13, June 10

Volunteer and AIDS Care Team Training is held on the *second Saturday* of each month (9 a.m. - 4 p.m.). Upon the completion of a training event, individuals are then eligible to volunteer through any of the sponsoring AIDS service organizations (A Baby's Place, AIDS Task Force of Alabama, AIDS in Minorities, Birmingham AIDS Outreach, or UAB 1917 Clinic).

Basic Training

Time: 8:30 registration, 9-4
Where: First Presbyterian Church, 2100 4th Avenue North, Birmingham (please note location)
Cost: $10 (includes refreshments, lunch & handouts)
Reservations: 934-1917, Judy Bowers.

Monthly Support Available for Care Team Leaders

AIDS Care Team Leaders now have added support on the second Saturday of *every* month at the volunteer training sessions. Malcolm Marler will lead a monthly group from 2-4 p.m. for all leaders who are currently coordinating Care Teams.

Please call Judy Bowers, 934-1917, if you plan to attend the Care Team Leader Support each month.

Alabama AIDS Organization Highlight

Birmingham AIDS Outreach (BAO)
PO Box 550070
Birmingham, AL 35255
Phone: (205) 322-4197
Fax: (205) 322-2131

Contact Person: Madge Noland, Director of Operations.

Location: 205 32nd Street South, Birmingham, AL.

Hours of Operation: 9 a.m. - 5 p.m.

Mission statement: To improve the quality of life for people affected by HIV through direct services, advocacy, and education.

Goals: Provide direct services to those affected by HIV; Serve as an advocate for people affected by HIV; Reduce the further spread of HIV; Develop an adequate and diversified funding base; Monitor needs and gaps in service during the emerging crisis; and develop an accountable and responsible organization.

Services include: Emergency financial assistance, counseling, support groups, buddy program, transportation, moving help, housing assistance, resource center, food, clothes, medical equipment, Park outreach, Bar outreach, helpline, speaker's bureau, and post test education.

Volunteer needs: Food and clothes closet, organizing the resource center.

Hope for Humanity

by Barbara Watts

How can I look into your face and speak words of comfort and courage for the future when I feel so helpless to calm your fears, to take away your pain, when I feel so afraid for you, so afraid for myself.

I feel little fear of the disease that is present in your body, but I am overwhelmed by the disease of uncertainty that is festering within me.

I tremble and cry out in angry silence about the injustice of your disease, of all disease, for your pain, for all pain. "Where is my God, my loving God in all of this?" I question.

For a moment I panic, I want to run out of your room, in search of a sign, a sign that God is not dead, that He is alive and I am not alone, that we are not alone.

In my desperation to feel connected, I reach out and touch you.

We are eye to eye, flesh to flesh, bone to bone, cell to cell, woman to man, man to woman, woman to woman, man to man, all humanity blended in that one touch.

We leap over our human barriers of pain, of disease, of who you are, who I am, where we are, why we are.

In that moment as we touch, we speed across all time, before time was, after time has been, time now and time forever.

As we touch, eons of seconds, minutes, hours, days, months, years, all come together. I am present for you, you are present for me.

As we touch I am aware of the powerful presence of the Holy One who created us IN love, who created us TO love.

I feel a sense of peace, a sense of hope, hope for you, hope for me, and hope for humanity.

Rev. Barbara Watts is a volunteer chaplain with the UAB 1917 Clinic.

Want to write for the Red Ribbon?

Do you serve on an AIDS Care Team or as an AIDS volunteer and want to share your experience with others? Are you a professional working with persons who are affected by HIV and want to help the religious community understand your clients' needs effectively?

Maybe you are a clergy person who struggles with or has resolved educational issues relevant to AIDS ministry and would be willing to write about it. Maybe you are a family member, or a person living with HIV disease and you could tell part of your story to our readers.

Personal reflections, articles, volunteer needs, and educational events throughout the state are the kinds of material we are seeking. *RRR* reserves the right to edit all material. All submissions should be focused on helping to fulfill the mission of the AIDS Education and Ministry Project: "To teach individuals and congregations how to make a difference in the AIDS epidemic through compassion, education, and ministry development."

We are now printing *RRR* every other month. Next deadline is May 10th for the June/July issue. Please submit articles to Malcolm Marler.

New brochures!

We have just printed new, attractive brochures describing two programs of the AIDS Education and Ministry Project: *GRACE* and *AIDS Care Teams*. If you would be willing to distribute or display these brochures in your congregation or business, please call Judy Bowers, 934-1917.

When AIDS came to our church

by Roger Lovette

AIDS slipped into our church through a side door when no one was looking. It happened, for me, over two years ago from someone on the other end of a telephone line.

"Would your church be willing to take someone who is suffering from AIDS? They are moving back here and the church where the mother goes is nervous about his coming to church." "Sure," I said, "I don't think this would be a problem." Well, the mother came, looked around, and joined our church.

Months later the sick son came home. I visited him and told him he was welcome. He was more than a little wary about preachers and this church business.

Finally, he came one Sunday and was disarmed. People welcomed him. He felt at home.

We got to be friends. He continued to attend church. One day he told me he wanted to join our church and he did.

One of our Sunday School classes began to visit him. Some of our members became friends with his mother. People began to help. On his good days some of our folk took him to the movies, fishing and to eat out. As he got weaker, many visited. Some brought food. Others prayed. His Sunday School class met around his bedside.

As he got sicker we talked about his funeral. The things he loved to do and was most proud of. I assured him we would give him a great send-off when the time came and he laughed.

Toward the end, one Sunday morning, his Sunday School class took Communion to him. Surrounding his bedside the old words took on a new power. "Do this in remembrance of me..." That Communion wafer and juice was the last liquid he ever took.

When he died, his mother asked his Sunday School class members to serve as pallbearers. We talked at the service about his love of life and his courage in fighting AIDS. We struggled with our griefs. We reassured one another that God was with him and his family and with us all.

Those of us who briefly touched this life will never be the same. He gave us, I think, much more than we ever gave him.

He taught us about courage and joy of life and grace under terrible pressure--and how God is with us all. He taught us that people with AIDS are just like us--no more and no less.

Since that time, his mother has helped so many people with AIDS. She has counseled many mothers. She has reached out to the sick. "How in the world do you do it?" I asked. "It's the only way I can keep going."

Our church is solidly committed to helping people with AIDS and all those family members touched by this epidemic.

Sometimes it means to sit and hold a hand. Sometimes it means to say a prayer. To take a meal. To hear a confession. To just be there. It always means to care and to do whatever you can.

I grant you one thing. To be engaged in AIDS ministry will change you forever. Jesus said it in the last parable he ever gave: "Inasmuch as you do it unto the least of these...you do it unto me." Sitting there beside the suffering or talking to those in the other room waiting and anxious, I am not sure but I think--I think--I saw faintly, but unmistakably, the loving face of Jesus.

This religious business is funny. Who would have ever believed he would sneak up on us through a telephone line and a question about AIDS?

Dr. Roger Lovette is pastor of the Baptist Church of the Covenant on the southside of Birmingham. His church has an active AIDS Care Team of more than twenty persons who are caring for several persons living with AIDS.

AIDS Care Team Update

Isolation, Transportation, Caring for Caregivers

by Joe Elmore

Twenty-seven AIDS Care Teams are either fully organized and working, or are in various stages of formation in Birmingham, with additional teams in Jasper, Huntsville, Tuscaloosa, and Florence. Faith communities now involved include Baptist, Presbyterian, United Methodist, Episcopal, Lutheran, and Roman Catholic churches, and a Jewish temple.

Each team consists of a group of volunteers who are committed to providing social, emotional, physical, and non-proselytizing spiritual support to persons living with AIDS and their loved ones. Let me share with you a few stories.

AIDS Care Teams address the issue of *isolation*. One man moved to Birmingham because of his illness, and literally had no family or friends in the city. Members of a Care Team have become "family" to him, calling and visiting him, and welcoming him into their church community.

A Care Team leader and I visited a woman living with AIDS in her home prior to Christmas, to discuss how the team could offer practical support. The woman pointed to her tree, decorated with beautiful, handmade ornaments. "I have no one to share it with," she said. "Do you think members of the team would come over for a Christmas party in my home?" Days later, the party took place!

Transportation is a critical issue for persons living with AIDS. For one person and his mother, regular trips to the doctor were extremely difficult, due to the number of stairs from the second-floor bedroom, out the house, into the car. Then, following the tiring doctor's visit, the return trip was even a greater problem.

Now, prior to each trip, the mother calls a Care Team member regarding when they need to leave the house, and the team member is there to help get the man to the car. Then, prior to leaving the clinic, another call is made, and the team member meets them at the house to provide the needed support for getting back up all the stairs.

Caring for Caregivers is another service of Care Teams. A mother came to Birmingham to stay with her son. She was essentially by his side day and night. Even when she was able to get away, she was not comfortable driving in a strange city. A Care Team is assigned to her, to offer friendship, transportation, and the opportunity for her to get away for a few hours each week, as members of the team sit with her son.

These brief stories point to the practical service now being given to persons living with AIDS and to their family members and friends. However, the most significant result of this program is the meaning and blessing of relationships that have and will be formed--mutually shared by all persons involved.

Joe Elmore is coordinator of AIDS Care Teams with the AIDS Education and Ministry Project.

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HIV / AIDS MINISTRIES NETWORK
FOCUS PAPER # 31

A NETWORK OF UNITED METHODISTS AND OTHERS WHO CARE ABOUT THE GLOBAL HIV/AIDS PANDEMIC AND THOSE WHOSE LIVES HAVE BEEN TOUCHED

ABOUT THIS ISSUE
April 1996

IN FOCUS PAPER # 31

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Dear Network Members:

Focus paper #31 was written by Debbi Hood Johnson, a PLWA and AIDS activist, near the end of 1995, with a scheduled release in the middle of 1996. We publish it now in her memory. She was killed in a car accident on February 24, 1996.

Debbi's "I Wear a Red Ribbon," originally published in our Focus Paper #25, has touched thousands of people all around the world. We include a memorial to her in this issue.

Focus paper #30, on African American Church Models for AIDS Ministry, originally scheduled to be released in March, will be mailed in June.

HIV/AIDS Ministries Network Focus Papers are a publication of the Health and Welfare Ministries Program Department, General Board of Global Ministries, The United Methodist Church, Room 350, 475 Riverside Drive, New York, NY 10115. Phone: 212-870-3909. FAX: 212-749-2641. INTERNET: aidsmin@gbgm-umc.org.

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We have taken the unusual step of delaying production of the scheduled Focus Paper #30 on African American HIV/AIDS ministry models and resources in order to publish this special edition of our Focus Paper series as a memorial to the life and ministry of Debbie Hood Johnson.

I, like countless others, knew Debbie through her HIV/AIDS ministry on CAM and through her writings. I never had the privilege of meeting Debbie face to face or even hearing her voice through the telephone. Yet I had the privilege of being a small part of Debbie's journey with HIV/AIDS.

Debbie touched many lives through her association with the Computerized AIDS Ministries Resource Network (CAM) around the world. Her moving story "Why I Wear a Red Ribbon" has been used by people throughout Asia, Africa, Latin America and the United States to move individuals and communities from complacency to compassion, despair to hope, and judgement to reconciliation. Through the mediums of the electronic bulletin board and the World Wide Web Debbie's life influenced individuals brought together by a common concern for ministry with persons living with HIV disease.

In Debbie's death, we have experienced anew the significance of following in the Weslyan tradition that calls us to "do all the good one can, in all the ways one can, at all the times one can, by all the means one can, as long as one can." Debbie's life and ministry has provided us with a brilliant example of how modern technology can be used to nurture new communities of faith. Communities which embody for me the truthes of the Christian faith; grace, love, compassion, responsibility, hope and reconciliation.

Our most honest tribute to Debbie Hood Johnson will be how we respond to those around us whose lives are forever challenged and changed by HIV/AIDS. My prayer for all of us is that we will live up to Debbie's example.

Grace & Peace,

Rev. Charles Carnahan
Executive for HIV/AIDS Ministries

Keeping the Love Alive... Together
The NAMES Project AIDS Memorial Quilt

by Debbi Hood Johnson

Note: *Factual information and how to make quilt panels has been adapted from information published by the NAMES Project.*

Modest Beginnings

Photo by Cathie Lyons

Early in 1987, a small band of friends gathered together in a San Francisco storefront to document lives that they feared history would neglect. The leader of that group, Cleve Jones, impulsively spray-painted the name of a dear friend who had died with AIDS on a simple piece of cloth, the size of an adult grave. He felt compelled to keep his friend's name alive on this vivid piece of fabric.

Cleve's actions marked the modest beginning of The NAMES Project Memorial Quilt. His feelings of grief, pride in the courage of his friends who were dying with AIDS, and determination to hold people's attention moved the small group of men into action. They decided to create a memorial for those who had died with AIDS and, through this memorial, to help people understand the devastating impact of the disease, which some have called a new holocaust.

Small steps by a few men initiated a global movement. As awareness of the Quilt and its impact increased, so did participation. Thousands of people from all over the United States and the world sent their loved ones' homemade panels to San Francisco. Now the NAMES Project AIDS Memorial Quilt is the most visible symbol of the AIDS pandemic.

The Quilt Today

The mission of NAMES Project is "to use the AIDS Memorial Quilt to help bring an end to the AIDS epidemic." Its goals are to provide a creative means for remembrance and healing, to illustrate the enormity of the AIDS epidemic, to increase public awareness of AIDS, to assist with HIV prevention education, and to raise funds for community-based AIDS service organizations.

The Quilt has also helped to move more people of faith into action. Cathie Lyons, former associate general secretary of Health and Welfare Ministries has written:

> *"To be in the presence of the Quilt, to experience its message and emotions is to be in the presence of the Holy: to be upheld and sustained by the knowledge that God's mercy has no end, that God's love endures, that God has received those who have died, and that the wounds of the living will be healed."*

As of October 1995, over 31,000 individual panels had been submitted for inclusion in the Quilt. Each panel measures 3 feet by 6 feet, symbolizing the size of an adult grave. If those 31,000 panels were spread out, side by side, they would cover 12 football fields without walkways, 18 football fields with walkways.

The AIDS Memorial Quilt is a fairly accurate mirror of the pandemic, even though the vast number of panels represent only a very small percentage of those who have died with AIDS. Panels are variously sewn by mothers and fathers, sons and daughters, brothers and sisters, lovers, spouses, close friends, support group members, Sunday School classes, synagogues, neighbors, hospice workers, and even strangers who want to honor the memory of someone who has succumbed to the ravages of AIDS.

Photo by Cathie Lyons

Participation in the Quilt is world-wide. As of October 1995, 39 countries in addition to the United States have contributed panels, including Argentina, Australia, Belgium, Brazil, Canada, Chile, Cuba, Denmark, Dominican Republic, France, Germany, Guatemala, Hong Kong, Ireland, Israel, Italy, Japan, Mexico, The Netherlands, New Zealand, North Ireland, Norway, Poland, Romania, Russia, Rwanda, Senegal, South Africa, Spain, Suriname, Sweden, Switzerland, Thailand, Trinidad and Tobago, Uganda, United Kingdom, and Zambia.

Just as the many countries represented in the Quilt offer a worldwide kaleidoscope of love and compassion, so do the fabrics and materials used to honor individual memories. One can get a real sense of the person's personality and life just by taking notice of the amazing range of items sewn into the panels, such as personal photos and drawings, religious symbols, dolls, Mardi Gras masks, feather boas, cowboy boots, cremation ashes, tennis shoes, taffeta, silk flowers, wedding rings, baby rings, scripture quotations and other inspirational writings, love letters, car keys, credit cards, blue jeans, motorcycle jackets, dresses, baby gowns, and stuffed animals. The creativity shown in the panels represents hours and hours of planning, drawing, cutting, sewing, laughing, crying, grieving and remembering.

The entire AIDS Memorial Quilt was shown most recently in October of 1992 in Washington, DC at the foot of the Washington Monument. More than 22,000 panels were displayed that weekend, with over 2,000 new panels presented for dedication and inclusion. The Quilt had been shown two previous times in Washington, DC... On each occasion, the planners of the display thought "never again" would the quilt be shown in its entirety because of its massive size.

Nevertheless, the Quilt will be seen "one last time" in Washington, DC in October of 1996. This October, the Quilt will span the entire length of the Mall, from the Capitol Building all the way down to the Lincoln Memorial.

Personalizing the Quilt

I can't write this article about The NAMES Project AIDS Memorial Quilt without personalizing it. My husband BJ died with AIDS in May of 1993. I am now living with AIDS myself. BJ And I were volunteers for The NAMES Project for the Quilt's first partial display in our home city of Charlotte, North Carolina in 1990. As local AIDS educators, we knew many of the individuals whose lives were represented on the panels. We were monitors for the display, to insure that no disruptions were made and that no one tried to deface the Quilt. We also served as grief counselors even as we experienced our own grief. We not only recognized some of the names on the panels, but also grieved to watch our friends and clients walk or be wheeled around the Quilt, knowing that soon their names would be sewn onto fabric.

The second time the local chapter of The NAMES Project brought a Quilt display to Charlotte, we were even more involved. We participated in the breathtaking opening and closing ceremonies, unfolding and folding quilt sections. Reverently we took turns at the podium reading names of the individuals represented in the display. We offered our shoulders as folks cried in front of panels. We explained how to prevent the transmission of HIV to young people, who came on busloads to view the unique memorial.

Photo by Debbi Hood Johnson

Because our city did not have a history of being supportive of AIDS issues, sponsors decided to have added security of volunteers sleeping at the Quilt site overnight. My husband BJ

and I shared a night with the Quilt. I cannot fully describe what it was like to be in the vast, silent auditorium with these mystical, spiritual pieces of cloth. That night we wandered slowly through the room, silently absorbing the love and pain reflected in each panel. We could almost hear the voices of those whose lives had been reduced to laminated photographs, handwritten letters, special teddy bears, pockets of ashes, and birth and death dates. The enormity of AIDS' impact---not only on those infected with HIV/AIDS but also those affected with HIV/AIDS---washed over us.

We camped on the cold concrete floor beside the traditional "signature panel", where people write messages to loved ones or simply sign their names as witnesses to the experience. We took our red ribbons off of our shirts and entwined them on the panel, securing them with clear permanent tape. BJ held my hand as he wrote this message in black magic marker beside our merged red ribbons:

> *"Sleeping with the Quilt brought an intimacy few have been privileged to experience. In doing so, we carry the names of those lost to HIV/AIDS and celebrate those who are living with HIV/AIDS. We renew our commitment to each other and the fight against ignorance. We're still keeping the love alive...together. We remember their names! June 20, 1992. BJ and Deb"*

Several months later, BJ and I packed our car and drove to Washington, DC to be a part of the "final" display of the entire Quilt. Again, we acted as unfolders, readers, and grief counselors. As we read the names together in front of that awesome lawn of colors, we heard our trembling voices echo off of the Washington Monument. We experienced such a feeling of community with so many unfamiliar faces. I was heartbroken to watch my husband walk down the black plastic walkways between the sections of panels. I knew this would be the last Quilt display we would share together in person. Seven months later, BJ was dead from AIDS.

Making BJ's Quilt Panel

I could not plan a panel for BJ until almost a year after he had died. I started by doodling and jotting down ideas as they came in my head. How could I compress his life and impact onto a 3'x6' piece of material? How could I design something that would be inclusive of all the family and friends who wanted to share in this memorialization? Finally, after many crumpled pieces of paper, I came upon just the right idea. I sent a draft drawing and letter with instructions and a deadline to this special group of folks, explaining how they could contribute to BJ's panel. Months and months of sketching, sewing and painting, gave birth to Beej's panel.

BJ's mother, sister and nephew accompanied me in the Quilt Dedication ceremony. As I passed the heavy folded material into the hands of The NAMES Project representative, a real peace came over me. I watched Quilt volunteers unfold BJ's panel and raise it up for everyone to see. On a Carolina blue background sat a teddy

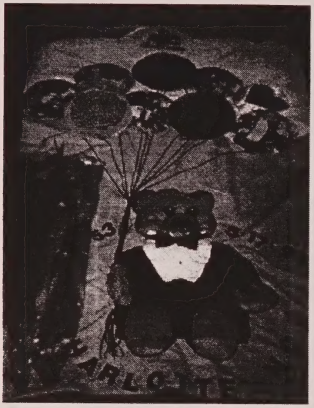

Photo by Debbi Hood Johnson

bear in a tuxedo, holding ten colorful balloons. Each balloon had been created by one of BJ's loved ones:

- His mother cross-stitched a poem she had written for him on a bright red balloon;
- A close friend had made a fabric collage of special photographs in his balloon;
- His sister summed up their special times together with code words and special phrases on a bright yellow background;
- I transferred one of our wedding photos onto a balloon;
- Other friends airbrushed drawings, sewed broken hearts onto satin, and painted in a blue balloon the yellow words *"Death is not extinguishing the light; it is putting out the candle because the Dawn has come."*
- At the top of the group of balloons was a special balloon where a fellow board member of our local NAMES Project chapter sewed on The NAMES Project name and logo.

I have not seen my husband's panel since it was sewn into a 12'x12' section of the Quilt [*ed. note: Debbi did get to see his panel one more time before her death.*); our local chapter hopes to have it shipped here for World AIDS Day, December 1. BJ would have been proud to have become a part of the AIDS Memorial Quilt, because he knew what an educational tool it has become. My heartfelt wish is that people all over the world, especially young people, will look at his panel and see how much this particular individual with AIDS was loved and cherished and understand how tragic it was for his life span to have been so short.

Although I dearly miss my husband, BJ, every day of my life, I am so glad he is represented in the AIDS Memorial Quilt. I plan to go back to Washington, DC next October for the next "final" display of the Quilt in its entirety. I'm sure that I will have mixed emotions as I stand in front of his panel or read his name from the podium. As precious as this roving museum is, I pray for the day there will be no more panels to be added to it. I pray for the day the sewing machines stop whirring. I also pray that someone will want to remember my name and make a panel for me....

I Wear a Red Ribbon

by Debbi Hood Johnson

People often ask me why I wear a Red Ribbon. Some people ask the question simply to find out what the ribbon means, but other people are really asking a hidden question: they wonder what experience in life has moved me so that I would want to wear a Red Ribbon, a visible reminder to all who see me of the continuing battle against HIV and AIDS. They are asking why I, a white heterosexual female in the heart of the conservative South, would choose to take an often unpopular stand, instead of quietly going about my life. Unknowingly, they are asking about my husband, BJ.

BJ made me his wife, but AIDS made me his widow. He died in my arms at 1:45 a.m. on Monday, May 17, 1993, in the little white house we had moved into only two days earlier. Surrounded by packed boxes filled with our books, our music, our photographs, and other mementos of our life together, we lay in the dark on the hospital bed provided by Hospice. Consumed, at this point, by massive brain lesions caused by PML (Progressive Multifocal Leukoencephalopathy), Beej had lapsed into a coma hours before.

Earlier that day his wonderful parents and our supportive friends, our "family of choice," had come, encircling his bed to say their soft good-byes, kiss his cheek gently, and whisper final messages into his ears as the room began to fill with the loud, bone-chilling sound of fluids collecting in his lungs as he struggled to breathe.

In our private final hours, I sang to him, prayed over him, and recited the 23rd Psalm over and over as I carefully brushed his long hair. I reminisced aloud about how we met and some of our favorite "heart snapshots"-- those special memories and private jokes and tender moments we had shared for so long. I chose to believe BJ could still hear me through the curtains of his coma.

As I sang one of our most special songs to him, I suddenly noticed my voice was no longer competing with the loud gurgling "death rattle" of BJ's breathing. I sat up on the bed and saw that his eyes were open-- he was looking at me. I knew he could really see me once again and that he could see that I was truly with him until the end. His face looked so serene, with a slightly lopsided grin.

"Go ahead, sweetie," I whispered hoarsely as I held him, "it's okay to let go now." As I kissed his lips for the last time and felt his life leave his body, my hand stayed on his chest, where his body heat remained the longest. I sobbed as I felt the chill spread; the warm spot over his heart grew smaller until it was no more. Another brave warrior in the fight against AIDS had fallen.

Why do I wear the Red Ribbon? I wear it because I CAN. I am still alive, still able to carry the message about the reality and urgency of AIDS and how HIV can be prevented. I carry this message for those whose voices can no longer be heard but whose presence can still be felt. What message is that? I carry the message-- to all who will hear AND listen-- that HIV/AIDS is, at this point, 100% FATAL... but it is also 100% PREVENTABLE.

I carry the message that Persons Living with AIDS (PLWAs), or-- as I heard recently from a feisty long-term survivor-- PLISOAs (Persons Living In Spite of AIDS) are PERSONS first and foremost:

- persons who have families and loved ones,
- persons who have dreams and hopes and fears,
- persons who laugh and cry,
- persons who deserve the same respect as you and I.

The gay community, for more than a decade, has shown us an incredible example of what unconditional love and honest, unflinching AIDS prevention education can accomplish. What about the rest of us? Where are the mainstream churches? I have been dismayed by stories of persons picketing AIDS funerals with hateful signs or quietly asking HIV-infected families to leave their congregations so that the tithes and offerings won't diminish.

I know that these hurtful actions are not the only witness of churches. Others have heeded Jesus' message in Matthew 25:35-45 ("...I was sick and you visited me...").

When I wear the Red Ribbon, I am demonstrating my compassion and care for people living with HIV/AIDS, my determination that those who have already died from AIDS-related causes will not be forgotten, my support for the ongoing efforts of all AIDS service organizations and researchers, my respect for the dedicated caregivers, and my desire to educate others about how to halt the spread of this obscene plague.

I can think of many other reasons to proudly wear the Red Ribbon, and these reasons have names and faces:

- Bill, the first PLWA I knowingly met and for whom I became one of Charlotte's first volunteer AIDS Buddies;
- David, the quiet man whose face had become a macabre mask of purple Kaposi's Sarcoma lesions;

- Daphne, the woman who fretted about who would care for her children after she had died;

- Tony, the entertainer who hung himself in desperation, afraid of how AIDS would continue to ravage his mind and body;

- Curtis, the proud African American who had such a big heart and tried to alert his community to its risks before hislife was cut short one Christmas;

- Little Jessica, whose panel in The NAMES Project AIDS Memorial Quilt haunts me to this day with its stuffed animals and baby blanket;

- Ryan White, whose unyielding courage showed the world that AIDS might sap his strength but never bend his spirit;

- Ron, whose independent streak continued until he drew his last breath in his apartment, surrounded by his friends and beloved cat; and

- BJ, my sweet, gentle husband, who never passed up an opportunity to speak to groups to educate them and to "put a face on AIDS."AIDS finally robbed him of his speech, his mobility, his bodily functions, his smile-but never his dignity.

There are those who believe the Red Ribbon has lost its meaning, that it's only an empty symbol now. I disagree! As long as my Red Ribbon gives someone the opportunity to ask me a question about AIDS, or gives someone the strength to go through another day encouraged by this small sign of support and solidarity, then its message is very clear:

The Red Ribbon simply means that I care.

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About the Author

Debbi Hood Johnson was killed in a car accident in North Carolina on February 24, 1996. A board member of the NAMES Project, Debbi lived in Charlotte, North Carolina, where she was an AIDS educator/counselor for about ten years. Debbi was one of the persons featured in the event 24 Hours in Cyberspace on February 8, 1996. A photojournalist spent 24 hours with her, documenting a day in her life as a PLWA (person living with AIDS), AIDS educator, and counselor and the role that support communities on electronic bulletin boards played in her life and in the lives of many PLWAS and their loved ones. Her friends are making a Quilt panel for her.

How to Make a Panel for the Quilt

The main qualifications for doing a Quilt panel are love of the person who has died and a desire to remember that person in a concrete way that will help witness to the world who that person was. You do not have to be a professional artist or a sewing expert to create a moving personal tribute. It doesn't matter if you use paint or fine needle work; any technique which will endure the folding and unfolding of quilt panels is appropriate. Although you may choose to create a panel privately as a personal memorial to someone you have loved, the NAMES Project encourages you to follow the traditions of the old-fashioned quilting bees and to include friends, family, and co-workers .

When you create a panel, draw upon your imagination and your memory of your loved one. Include the name of the friend or loved one being memorialized and additional information such as the dates of his or her birth and death and a hometown. The NAMES Project asks that each panel be limited to one individual (although one individual may have more than one panel).

Durability of materials used for the panel is crucial. A medium-weight, non-stretch fabric (such as cotton or poplin) works best. Your design can be vertical or horizontal, but the finished, hemmed panel must be exactly 3 feet by 6 feet (90cm X180cm). When the fabric is cut, be sure to leave an extra 2 or 3 inches all around the hem. If you can't hem the panel yourself, send it to The NAMES Project (finished except for the hemming). Volunteers at their headquarters will hem it for you. Batting for the panels is not necessary but please use backing. Backing helps keep panels clean when they are laid out of the ground and helps retain the shape of the fabric.)

Photo by Cathie Lyons

As you construct your panel, the NAMES Project suggests that consider using some of the following techniques:

Applique´: Sew fabric, letters, and small mementos onto the background fabric. Do not use glue. Remember all the folding and unfolding! The glue won't hold very long.

Paint: Brush on textile paint or colorfast dye, or use an indelible ink pen. Do **not** use "puffy paint", however; it makes a mess.

Stencil: Trace your design on to the fabric with a pencil; lift the stencil; then use a brush to apply textile paint or indelible makers.

Collage: Don't use materials you on the panel that will tear the fabric. For example, avoid glass and sequins and very bulky objects.

Photos: Photocopy photos or letters onto iron-on transfers, iron them onto 100% cotton fabric and sew that fabric to the panel or put the photo in clear plastic vinyl and sew it to the panel off-center so it avoids the fold.

Once you complete your panel, please take the time to write a one or two page letter about the person you've memorialized. The letter might explain the symbolism of parts of the panel, your relationship to him or her, how he or she would like to be remembered, a favorite memory, or all of the above! If you can, send a photograph of the persons with the letter for The NAMES Project's archives.

Additional Information

Quilt Displays
If you want to bring a portion of The NAMES Project AIDS Memorial Quilt to your city for a display, you can contact the Quilt Headquarters for the name and information about the local chapter closest to you. Congregations may also ask for information about the interfaith Quilt Project.

The NAMES Project's Visitors' Center and Panelmaking Workshop can be reached in San Francisco at (415) 863-1966. Their main office is at 310 Townsend Street, Suite 310, San Francisco, CA 94107 (phone: 415-882-5500, fax: (415) 882-6200).

Websites
The NAMES Project is also on the World Wide Web at http://www.aidsquilt.org. The website has information about how to make quilt panels, the display in Washington, DC in October, pictures of some of the panels, AIDS educational information and more.

Health and Welfare Ministries sponsors an AIDS Memorial web site at http://gbgm-umc.org/CAM/memorials. See article in this Focus Paper for information on how to submit material to this website.

Remembering Loved Ones Who Have Died from AIDS on the World Wide Web

Health and Welfare Ministries posts memorials free of charge to persons with HIV/AIDS who have its Computerized AIDS Ministries (CAM) website at http://gbgm-umc.org/CAM/memorials. At this time, we also do free HTML markup posting, although volume may prevent us from continuing this practice at an undetermined time in the future. We reserve the right not to post a memorial if it seems inappropriate for this sacred space, but do not expect that we will have to invoke that right.

General Guidelines

1. Please make a statement that you give permission to the General Board of Global Ministries to post the memorial on its AIDS Memorial Web Site and that this post does not violate confidentiality in terms of a person's AIDS diagnosis and its impact on the person's loved ones. Note any other stipulations also concerning reproduction of the memorial by others.

2. Generally Memorials should be 250-750 words long.

3. Memorials should include the name of the person who died and, if possible, the birth and death dates, at the beginning of the memorial.

4. Memorials should include the name of the author(s) and the date they were written at the end of the memorial.

5. Memorials may be narratives, letters, poetry... a variety of forms. Graphics that add to the statement of the memorial, such as photos of the loved one and/or his or her quilt panel(s) may be included. These will be in GIF format on the web, not to exceed 100,000 bytes and may be sized down, to enable a page to load quickly.

6. Memorials are to be appropriate for this sacred space and for persons of all ages to read.

7. Any editing beyond typos that we do of a memorial with be in consultation with and with the approval of the author.

Submission of Memorials

Send memorials to:

1. aidsmin@gbgm-umc.org in ASCII; or HTML format;

2. or FTP them to hwbbs.gbgm-umc.org. CD into the EVENTS library and put them there;

3. or sign up as a member of CAM (Computerized AIDS Ministries--modem number 212-222-2135) and upload them the material to the MEMORIAL library after you have been upgraded, sending a note to sysop that you have put them there. (Anonymous FTP does not have access to the MEMORIAL library)

4. or send then files on an IBM-compatible disk to:

AIDS Memorial Web Pages
Health and Welfare Ministries, General Board of Global Ministries
The United Methodist Church
Room 350
475 Riverside Drive
New York, NY 10115

Written material should be in ASCII or HTML format. Graphics should be in GIF format. Graphics may be FTPed to the EVENTS library or sent by disk along with the memorial.

The Least of These Are My Family

Nancy A. Carter

Saturday, March 16, 1996
Charlotte, North Carolina
Memorial Service for Debbi Hood Johnson

Thirteen years ago this spring, my life changed radically. A friend of mine, Charles Bergner, was diagnosed with AIDS. Like many of us in 1983, I had barely heard of AIDS. Charles was an active member of the church I attended, Washington Square United Methodist Church in New York City. We made an active decision to not only support Charles as he faced this new illness but also opened our doors to persons with HIV and AIDS in a variety of ways. We offered free meeting space, a place for memorial services, and pastoral care. I personally decided, like the church, to support Charles, to visit him, to be with him. Little did I know that my decision would lead me to where I am today, not just generally in terms of my overall ministry but quite literally where I stand right now, here in Charlotte, North Carolina.

Everyone in this room can remember a time when an awareness of AIDS entered our life. Probably most, if not all of us, can also say that AIDS has changed our lives radically. Certainly this was true for Debbi Hood Johnson when she made some bold decisions about ten years ago to enter into ministry with people with AIDS. She could not have known where her chosen path would lead her-- that she would gain friends who loved her and became her "family of choice" --that she would meet and marry B. J. Johnson, her beloved husband who died of AIDS about three years ago-- that she would be loved and respected by people all around the world who never met her face-to-face but had read her "I Wear a Red Ribbon" or talked with her on electronic bulletin boards, such as CAM and America on Line, or through Internet e-mail. Today is the first time some of us from Debbi's Charlotte community and Debbi's online community have met. She could not have foreseen this kind of gathering either, at least not at the beginning of her journey with AIDS.

As part of her witness to the world, Debbi wore the Red Ribbon proudly... and courageously, given the prejudice against people with AIDS that existed and still persists. Near the end of her life, Debbi even had the Red Ribbon tattooed on her wrist! Debbi declared, "When I wear the Red Ribbon, I am demonstrating my compassion and care for people living with HIV/AIDS...."

Debbi believed that Matthew 25 and Jesus' words to the righteous, "I was sick and you visited me" are a clear divine mandate to be in ministry with people with AIDS, to treat people with AIDS with the utmost of love and respect. In "I Wear a Red Ribbon," she challenged churches and communities to respond to Christ's call, saying:

> The gay community, for more than a decade, has shown us an incredible example of what unconditional love and honest, unflinching AIDS prevention education can accomplish. What about the rest of us? Where are the mainstream churches? I have been dismayed by stories of persons picketing AIDS funerals with hateful signs or quietly asking HIV-infected families to leave their congregations so that the tithes and offerings won't diminish.
>
> I know that these hurtful actions are not the only witness of churches. Others have heeded Jesus' message in Matthew 25.... "I was sick and you visited me...."

Debbi lived out Jesus' mandate to be in ministry with people who are sick.

Let's look at this parable that is unique to Matthew and touched Debbi so deeply. Sometimes it is called the Parable of the Sheep and the Goats. The sheep symbolize people who are righteous, who make justice a part of their way of life. The goats symbolize people who are not righteous, who are not just.

Notice that the sheep and goats are defined by their actions, not their words, or even their beliefs. In the gospel of Matthew, good words are not enough to receive God's blessing; neither is acknowledging Jesus as Lord. (Clearly both the sheep and the goats acknowledge the king, who symbolizes Jesus, as "Lord," and show great respect to him.) Good words and respect for the Lord must be joined with righteous actions, works of justice.

The message of Matthew 25 is clear in terms of ministry with persons who have an illness. Righteous people visit people who are sick. Unrighteous people do not. In our day and age, Jesus would say that righteous people visit people with AIDS.

According to Matthew 25, visiting people who are sick is not something we do simply to pat ourselves on the back and make ourselves feel good. Neither is it a time to take on an air of self-righteousness and judgmentalism.

Jesus says, "just as you did it to one of the least of these, who are members of my family, you did it to me." Did you hear that radical message? Jesus says that the least of these, such as persons who are sick with HIV/AIDS, are his family--that is, they are children of God. Righteous people visit those who have AIDS as an expression of close kinship or relationship.... Debbi understood and lived this command of Jesus. Through her writing and her day-to-day actions, Debbi witnessed to the world, saying, "I carry the message that Persons Living with AIDS... are PERSONS first and foremost: persons who have families and loved ones, persons who have dreams and hopes and fears, persons who laugh and cry, persons who deserve the same respect as you and I."

But wait. Jesus' message goes even further than declaring that "the least of these" are his family. He says that whatever we do to his family members, we do to him. People

who have AIDS are to be treated as if they are Jesus Christ personified. Whatever we do or do not do to people with AIDS, we do it to the Christ, to the very Presence of God on earth.

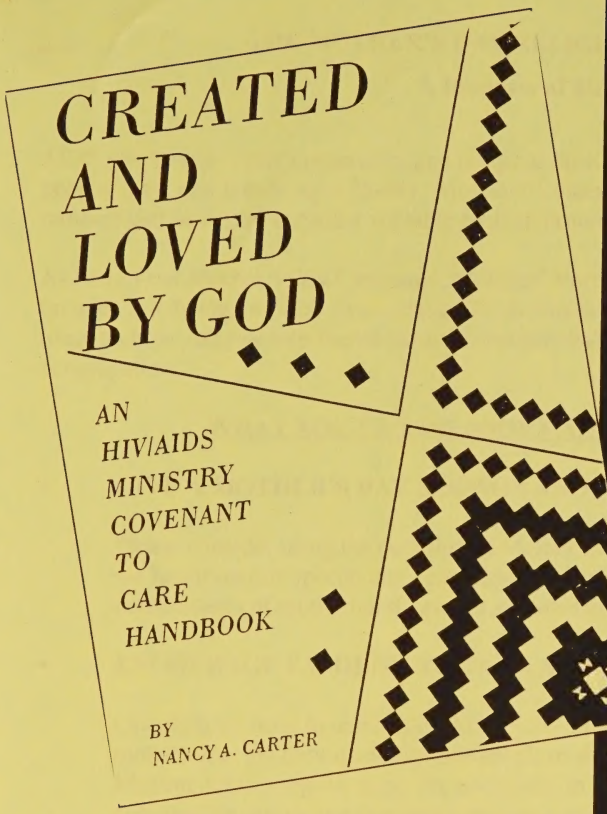
Debbi Hood Johnson treated people with AIDS as if they were the very Presence of Christ. She wrote:

> People often ask me why I wear a Red Ribbon... why I, a white heterosexual female in the heart of the conservative South, would choose to take an often unpopular stand, instead of quietly going about my life.... Why do I wear the Red Ribbon? I wear it because I CAN. I am still alive, still able to carry the message about the reality and urgency of AIDS and how HIV can be prevented. I carry this message for those whose voices can no longer be heard but whose presence can still be felt.

We were not prepared for Debbi to die so soon. We believed she would be with us a while longer. Who would have thought that a car accident, rather than AIDS, would have taken her life so abruptly.

Now Debbi's voice can no longer be heard but we can still feel her presence. We have some of the words that she wrote, the photographs that she took, the cards she sent us. We have her memory.... her witness...

Now Debbi is more fully in the Presence of God, who most certainly counts her among the sheep and calls her blessed saying, "I was sick and you visited me..."



HIV/AIDS MINISTRY RESOURCE

Created and Loved by God: An HIV/AIDS Ministry Covenant to Care Handbook by Nancy A. Carter

A comprehensive guide for local congregations and annual conferences to use to develop HIV/AIDS ministries. It provides biblical and theological background, program ideas and plans, and materials for information and duplication which every congregation can use. No church should be without this valuable resource.

Send order with remittance to: Service Center, General Board of Global Ministries, The United Methodist Church, 7820 Reading Road, Caller No. 1800, Cincinnati, OH 45222-1800, or fax order to (513) 761-3722 ($1.50 billing fee on fax orders.)

---------- TEAR OFF SLIP TO ORDER ----------

CREATED AND LOVED BY GOD: An HIV/AIDS Ministry Covenant to Care Handbook

Please send___copies of CREATED AND LOVED BY GOD: An HIV/AIDS Ministry Covenant to Care Handbook (#2149) @$4.95 plus postage and handling. Make check payable to Service Center.

Total copies this order____(@$4.95) $_____
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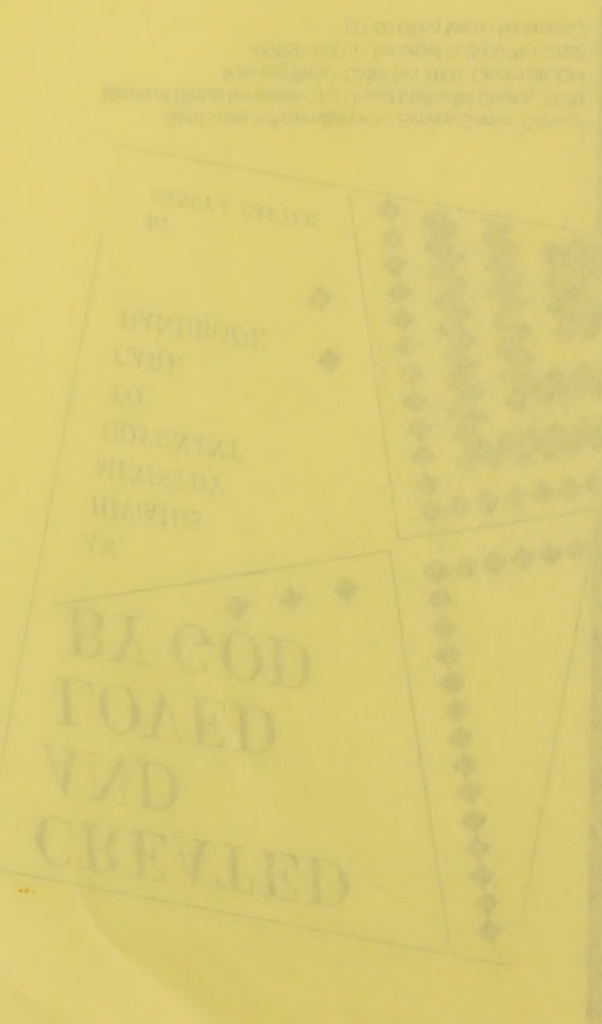

BY GOD
LOVED
AND
CREATED

THE MOTHER'S DAY RELIGIOUS OUTREACH ON AIDS

A Program of Mothers' Voices

AIDS now affects every community and religious faith (AIDS is now the leading cause of death for young people, male and female ages 25-44). Mothers' Voices believes that the moral authority and power of mothers can be one of our most valuable tools in promoting AIDS education, prevention and research.

As part of our Mother's Day Campaign, Mothers' Voices is working with religious leaders of all faiths to broaden the dialog on AIDS in congregations across the country. We have prepared this outline to offer ideas on how you can help facilitate this important dialog between mothers and families in your congregation.

WHAT YOU CAN DO ABOUT AIDS IN YOUR CONGREGATION

- **GIVE A MOTHER'S DAY SERMON ABOUT AIDS**

  Please consider using the occasion of Mother's Day to create a sermon promoting the virtues that we honor on this special day - compassion, protection, education, and love. These are the cornerstones of motherhood, and the values that can help us end AIDS.

- **ENCOURAGE FAMILIES TO TALK ABOUT AIDS**

  Our children need to understand AIDS. Try to make your congregation a welcoming place where mothers can get their questions answered, so that they can become better teachers themselves. Making AIDS a regular topic for discussion in your congregation will help families feel more comfortable discussing this important issue at home.

- **MAKE AIDS EDUCATION PROMINENTLY AVAILABLE IN YOUR CONGREGATION**

  Your congregation is a resource to mothers on many aspects of family life. Make it a resource for information on AIDS as well. Some religious faiths produce their own AIDS education materials. Or, you may choose to provide information produced by an AIDS service organization. For example, Mothers' Voices is beginning a new Internet Web site that will serve as a resource center on AIDS for mothers and will include pointers about how mothers can educate their children about sexuality, including the prevention of AIDS.

  Having AIDS information available in your congregation will also send a clear message that persons at risk for AIDS or affected by the disease will find a supportive place to discuss their questions and problems.

- **TELL YOUR CONGREGANTS ABOUT MOTHERS' VOICES**

  Sometimes a mother needs to hear from another mother who has had similar problems, questions, or concerns. Please use Mothers' Voices as a resource for yourself and for the mothers in your congregation who need information about AIDS. We are available for you or your congregants at 1-888-MVOICES.

Contact: Greg Lugliani or Scott Williams, (415) 882-5500

The Quilt in the Capital

Entire NAMES Project AIDS Memorial Quilt To Be Shown in Washington, D.C., October 11-13, 1996

Since it was started eight years ago, the AIDS Memorial Quilt has chronicled, sometimes grimly, sometimes beautifully, always powerfully, the ravages of AIDS on American society. As it records the history of life in this time of plague, the Quilt consoles the grieving and calls attention to the uniqueness of human life. It advocates for a reasoned and humane response to the epidemic, and demands action from our nation's leaders to bring the dying to an end.

No other symbol speaks so eloquently of the international tragedy of AIDS; none so clearly unites the HIV-infected, the HIV-affected, and the AIDS-phobic. As the largest community arts project in history, the Quilt's visual commemoration of lives sparks a dialogue between those who make panels and those who view them— a conversation that allows us to talk about two topics which our society often finds difficult to discuss: sex and death.

Seen by over one million people in more than 2,000 different locations each year, the Quilt is the humanity behind the cruel statistics of AIDS; and no matter where it is displayed, the Quilt shows how AIDS has touched every community in America.

Yet even in the epidemic's second decade, political consensus about AIDS is elusive: research and treatment dollars dwindle; education efforts go unfunded. Despite being the leading cause of death among American men and women aged 25 to 44, AIDS is neither a legislative priority nor an urgent media story. With complacency about AIDS attaining new heights, the time has come again to force national attention on the epidemic by bringing the Quilt to Washington, D.C.

From October 11 to 13, 1996, just four weeks before national elections, The NAMES Project will display the entire AIDS Memorial Quilt on America's front lawn, the National Mall. As 45,000 memorial panels—30 football fields of fabric—are unfolded, the names of the dead will ring out over the open expanse. In all, 70,000 names will be read, more names than carved into the nearby Vietnam War Memorial. The litany of the names of the dead will continue unbroken for three days as 2,000 readers—elected officials, sports figures, celebrities, community and religious leaders, educators, people with AIDS, family members, friends—each take a turn at the podium.

(over)

310 Townsend Street, Suite 310, San Francisco, CA 94107-1639
Tel: 415/882-5500, Fax: 415/882-6200, e-mail: info@aidsquilt.org Website: http://www.aidsquilt.org

The Quilt in the Capital

Since its last showing in Washington in 1992, the Quilt will have doubled in size, and the need for volunteers has grown accordingly. Hundreds of eight-person teams from all over America will unfold the Quilt in the early hours of October 11, 1996; more than 10,000 volunteers will participate in the three-day display. An estimated 750,000 visitors are expected, including 50,000 school children. Over 26 miles of walkway fabric will allow people to get close to each memorial panel.

Planning for the world's most powerful depiction of the devastation of AIDS—and arguably the greatest demonstration of respect for those lost in this war against a virus—began a year and a half in advance of the event. The NAMES Project's 40 U.S. chapters and seven regional display committees are working closely with the San Francisco-based NAMES Project Foundation to recruit and train volunteers and help raise the $1 million needed to make this display happen. A gala fund-raising dinner will be held at the National Building Museum on Friday, October 11, and a Candlelight March Against AIDS will be held on the Ellipse on Saturday, October 12 at 7 p.m.

While the three-day event will attract tremendous public attention, the Quilt display will actually be the culmination of a year-long campaign of national awareness and education. Throughout this election year, the NAMES Project and AIDS Action Council are co-sponsoring *Remember Them With Your Vote*, an nation-wide voter education and registration campaign focusing on AIDS issues and policy. National media and public relations efforts will bring the Quilt into millions of American homes. Through various partnerships with AIDS service providers, advocacy groups, and educational organizations, the AIDS Memorial Quilt will help forge the national consensus and inspire the political will needed to defeat AIDS. It will allow us to grieve as a nation, and, as a people, to respond urgently and with compassion to those living with HIV.

Join the NAMES Project in Washington, D.C., October 11 through 13, 1996 for a celebration of lives, a renewal of commitment, and a call to action that will make a world without AIDS exist again.

THE NAMES PROJECT
AIDS Memorial Quilt

GENERAL INFORMATION ABOUT THE DISPLAY:
NAMES Project Travel Information: 800-926-2631
To Volunteer: 415-882-5569, ext. 366
To make reservations for the fundraising dinner on Friday, October 11: 713-523-5780

310 Townsend Street, Suite 310, San Francisco, CA 94107-1639
Tel: 415/882-5500, Fax: 415/882-6200, e-mail: info@aidsquilt.org Website: http://www.aidsquilt.org

FIRST IN THE FIGHT
AGAINST AIDS

GMHC

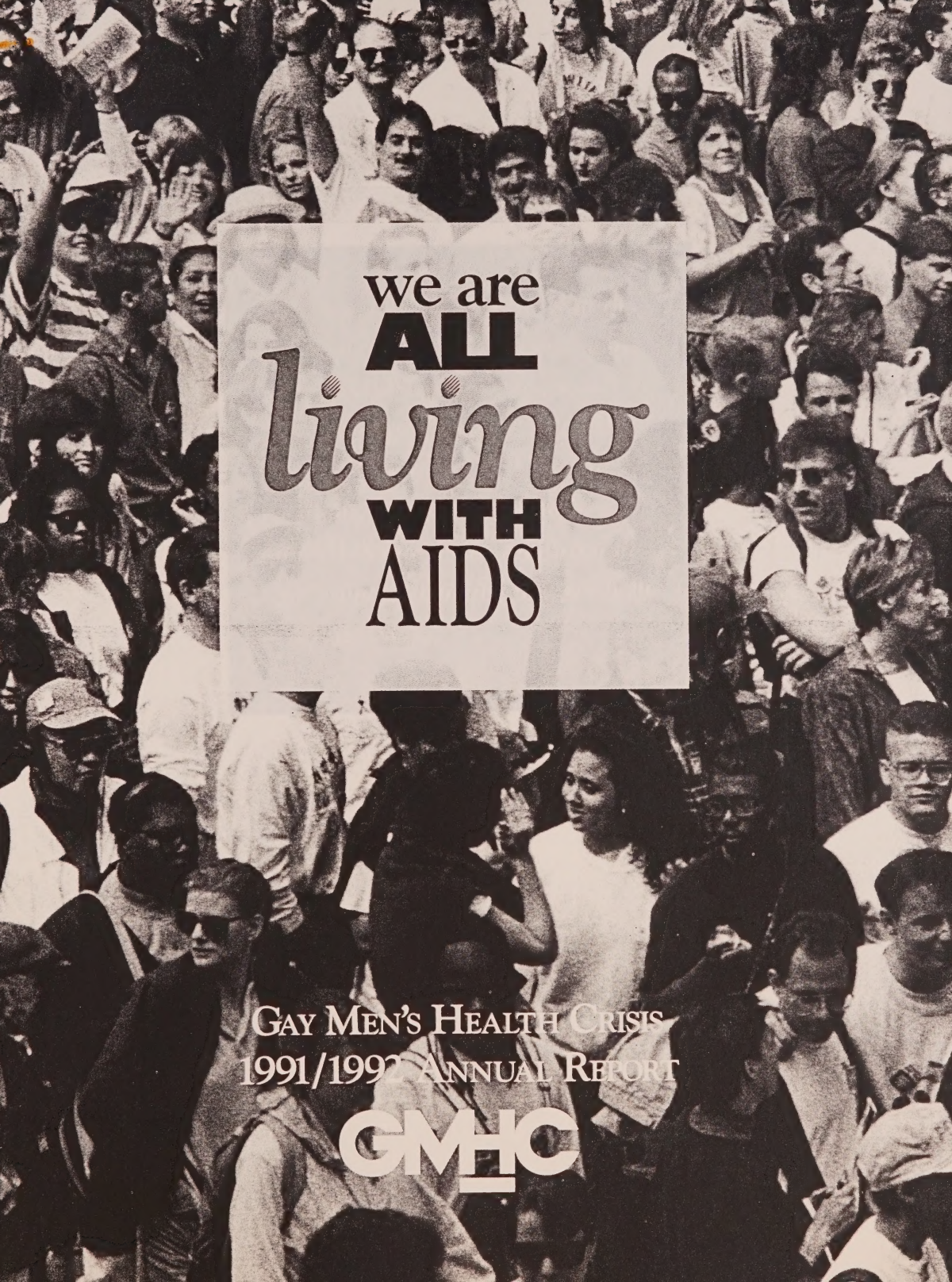
Dear Friend,

I am proud to send you the 1992 Annual Report on the activities of Gay Men's Health Crisis. Entitled *We Are All Living With AIDS*, this year's report includes the personal stories of GMHC clients, volunteers, Board members and staff. Their own words capture the complexities of the battle we are fighting more eloquently than statistical analyses or clinical descriptions ever could.

Your continued efforts on behalf of people with HIV allow us to face the enormous challenges the AIDS epidemic poses for us all.

Timothy J. Sweeney

Timothy J. Sweeney, *Executive Director*



Gay Men's Health Crisis

1991/1992 Annual Report

GMHC

This report is dedicated to the thousands of women with AIDS who remain uncounted because of a CDC definition of AIDS that excludes them — both from an AIDS diagnosis, and from the government benefits that can help them survive.

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Letter from the Board President and Executive Director

How do you measure success in the midst of an epidemic? Gay Men's Health Crisis (GMHC), the world's first AIDS organization, is now the world's largest. Our AIDS education and advocacy work are saving lives and forcing change nationwide. The services we provide free to New Yorkers with AIDS and HIV have grown to reach more than 14,000 men, women and children. AIDS cases, however, are growing far faster. Over 150,000 Americans have now died of AIDS — more than died in the Gulf, Vietnam and Korean Wars combined.

In this election year, it is hard to talk about AIDS without talking about a massive failure of national leadership. We began our fight in 1981, when there was nothing for people with AIDS: no services, no funding, no public information and no public outcry. Eleven years into this epidemic, we are still a community looking to itself in a crisis. The White House has devoted only one public speech to AIDS in the last four years. Congress slashed funding to the Ryan White CARE Act this year, delivering less than a third of the emergency relief promised to the cities hardest hit by AIDS. Government funding of GMHC, once 35% of our budget, has fallen to 15%. That we have done so much with so little should make us proud — and angry.

Pride is hard to sustain when 20 more New Yorkers are diagnosed with AIDS every day. At least one million Americans are infected with HIV, and that is a five-year-old estimate. If those statistics seem overwhelming, consider another set of numbers: over 40,000 meals served by GMHC's Recreation Program this year; 83,000 calls answered by GMHC's Hotline; 25,000 people who rallied in Times Square on July 14, 1992 to support United For AIDS Action, a coalition formed by GMHC and over 480 other organizations determined to make AIDS an election issue. We are setting an example of leadership our government should follow.

Where can *we* turn for leadership as we enter the second decade of AIDS? This year, GMHC's Board of Directors created a strategic plan to help guide GMHC's growth over the next three years. Among other things, the plan highlights the ways GMHC can build new partnerships with other AIDS organizations throughout the city, and reaffirms the principles that have shaped our work for the last decade: The belief that people with AIDS deserve power, not pity; a commitment to serving the gay and lesbian communities; and recognition of the crucial role that volunteers, staff and donors play in getting our work done.

This annual report captures another of the plan's themes — strength through diversity. When GMHC began, no one ever imagined that we would still be here fighting 11 years later. But we did imagine and create a new network of care, education and advocacy to reach all people with AIDS. We did it as a multicultural coalition, as men and women of different races, ethnicities and sexual orientations. Whether through new programs such as the Lesbian AIDS Project, or proven models like education programs for people of color and on-site 12-step meetings, we are recognizing that no single approach can meet the needs of the many communities being ravaged by AIDS.

The people who tell their stories in this report — some who have HIV illness and others who do not — are only a few of those who know what it means to be living with AIDS. Many more, not represented in these pages, are also speaking out and taking action to end this epidemic.

For all our differences, we share a common message: Volunteer. Donate. Educate. Advocate. In the fight against AIDS, ordinary people can make an extraordinary difference.

Jeff Soref, *President*

Timothy J. Sweeney, *Executive Director*

Mel Rosen (1950-1992)

We remember Mel Rosen, GMHC's first executive director and one of a handful of pioneers who stepped forward to fight for an end to AIDS. Mel led GMHC at the beginning of the epidemic, when AIDS was known as Gay-Related Immune Deficiency (GRID). Later, he became the first head of New York State's AIDS Institute. We will miss his commitment to the rights, dignity and well-being of people with HIV and AIDS. The spirit and value of his work live on.

Why Our Name?

It's a question people ask often. If Gay Men's Health Crisis serves men, women and children with AIDS, why continue to call ourselves Gay Men's Health Crisis? AIDS isn't only a gay disease. It never was. We might have an easier time raising money from both public and private sources if we were called, say, the "New York City AIDS Foundation," so why not change our name?

The answer lies in the history that we never want to lose. Eleven years ago, before AIDS even had its name, a small group of gay men formed GMHC to help sick friends and lovers cope. What those men pioneered — the world's first buddy program, the first medical newsletter, the first AIDS hotline — were one-of-a-kind, groundbreaking services that still serve as a model for AIDS care worldwide. The early volunteers chose to name their organization after their community because their community was fighting an epidemic the rest of the world ignored. The rest of the world didn't think it was at risk.

Today, GMHC is building on the expertise and experiences of the gay community to reach out to everyone with HIV illness. The name Gay Men's Health Crisis is a reminder of the past and a badge of pride. Our name lets people know that fighting AIDS means fighting the epidemic of discrimination that has helped kill so many so quickly: discrimination not only on the basis of sexual orientation, but also on the basis of race, gender and social status. Our name challenges people to break down stereotypes, put aside narrow definitions of self-interest, stop "us and them" thinking and start saving lives. We're not working to end AIDS because people who get it are gay, or straight, or men, or women, or hemophiliacs or injection drug users. We're working to end AIDS because we are alive and we don't want anyone else to die the way our friends and loved ones have died.

There is another part of our name — Crisis — that people tend to overlook. We work every day with waiting lists and clogged switchboards and the terrible sense that we need to do more. That urgency never leaves us. We have got to do more, and do it quickly. AIDS can't wait.

What We Do

GMHC has a triple mission: to provide services for people with AIDS and HIV; to prevent the spread of HIV and keep people healthy through education; and to advocate for the government leadership and funding that can bring us a vaccine and a cure. GMHC's services are available free to any New York city resident diagnosed with HIV illness.

Client Services helps people with the emotional and practical difficulties of living with HIV illness, offering services ranging from daily hot meals to long-term financial planning.

Legal Services offers help with the legal issues that confront people living with HIV, including wills, discrimination in housing, insurance and immigration, disputes with landlords and creditors, and child custody matters.

The Office of the Ombudsman investigates and resolves problems people with HIV encounter in hospitals, with insurance companies, in government offices and in other parts of the health care system.

The Education Department uses every method it can to get the HIV prevention message out — publications, videos, trainings, an AIDS hotline, safer sex workshops, and community outreach.

The Policy Department pushes all levels of government to save lives from AIDS, fighting for increased funding, better legislation, improved and more inclusive AIDS research and care. The Communications Department works with and through the media to support GMHC's advocacy campaigns and to provide accurate, up-to-date AIDS information to the public and to volunteers, donors and staff.

Who We Serve

We serve anyone diagnosed with HIV illness in New York City — men, women and children; African Americans and Native Americans, whites, Latinos and Asians. While people draw neat lines to divide gay men from drug users, whites from non-whites, or rich from poor, AIDS is not so particular. Three out of four of our clients are gay men. Just under half those we serve are Latino, Asian, African American or Native American, making GMHC one of the largest providers of services to people of color in New York City. Nearly 25% of our clients have a history of injection drug use, and nearly 80% are on Medicaid at some point in their illness.

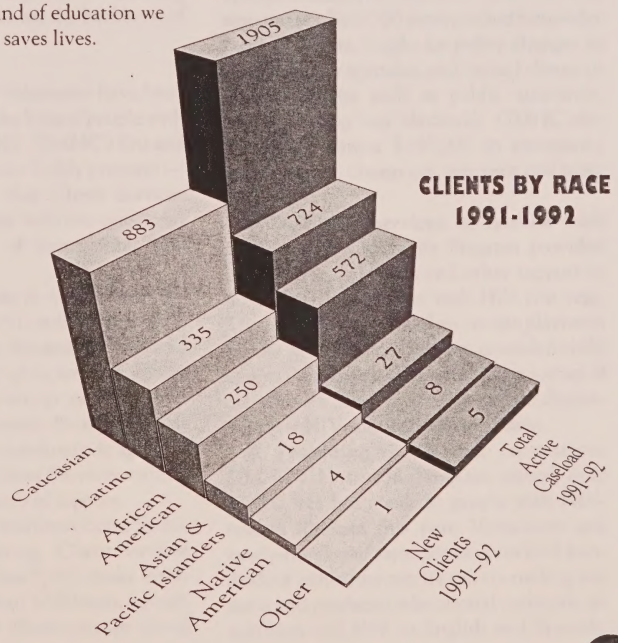
GMHC's volunteers, staff and Board of Directors, too, reflect the range of communities affected by the epidemic. Our 2,300 volunteers, 230 full-time staff members and 30 Board members are men and women of different ages, races, ethnicities and sexual orientations. Many are men and women who are living openly with HIV and AIDS.

How We Pay for What We Do

Generous gifts from several individuals and a large turnout at this year's AIDS Walk New York were the only things that came between GMHC and a cash deficit this year. With a very limited endowment fund, GMHC faces tremendous pressure every year to raise the money we need. The scale of our fundraising efforts has changed since early GMHC volunteers passed coffee cans among friends or set up card tables in front of gay discos. The crucial role played by private donations, however, remains the same.

An overwhelming 78.7% of GMHC's $20.3 million revenue budget comes from private donors — hundreds of thousands of individuals who recognize that every gift can make a difference. Nearly 52% of those private contributions are raised by GMHC's special events — the Dance-A-Thon, Circus For Life, and AIDS Walk New York, among others. Private corporations and foundations supply an additional 4% of our funding. Meanwhile, a corps of 2,300 volunteers continues to be a tremendous and unwavering source of support, contributing an estimated $2.5 million worth of labor to GMHC this year alone.

Government has proved a less committed supporter. The State AIDS Institute, which gave GMHC its first grant in 1983, is still a valued partner in our work, contributing $1.6 million. New York City contributed a vital $878,000 this year through its Department of Health and its Human Resources Administration, and GMHC was awarded $667,000 in federal Ryan White CARE Bill grants, to be spent over two fiscal years. But GMHC and many other community-based organizations are receiving virtually no other federal support even as AIDS caseloads skyrocket. Federal funding of GMHC's safer sex programs has been blocked since 1986 by restrictions against "offensive" materials. In May of 1992, after years of litigation, the American Civil Liberties Union, GMHC and other AIDS advocates had those absurdly vague restrictions struck down in federal court. We are still waiting for Washington to support the kind of education we know saves lives.



Volunteer to Stop the Crisis of Indifference

"What have you done today to end the AIDS crisis?" That boldly-stated question, once the answering machine message of one of GMHC's founders, still captures the sense of urgency and pragmatism that keeps volunteers coming to GMHC.

Our volunteer corps grew sharply this year. More and more New Yorkers have grown tired of watching their loved ones die without drugs to treat their illness and watching the rest of the world go about its business as usual. AIDS volunteers save lives and face death every day. They don't do it for salaries, or awards, or public recognition. They do it because it's a way to combat the pain and despair that comes from living — and dying — with AIDS.

Today, 2,300 volunteers are working in GMHC's offices, in our buddy and crisis intervention programs, as lawyers and therapists and peer educators. Thousands more serve as part of GMHC's telephone lobby teams, and take part in GMHC's special fundraising events. These individuals are the backbone of all of GMHC's work.

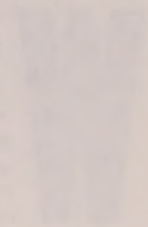
More than 3,500 men, women and children with HIV illness now use our client services.

CLIENT SERVICES volunteers have been making a difference in the lives of people with HIV and AIDS since 1982. GMHC's first and best known service — our buddy program — is now one of dozens that Client Services offers to help people deal with the emotional and practical aspects of living with HIV illness.

This year, GMHC had to make one of the hardest decisions in its 11-year history. Confronted by skyrocketing demand and the need to maintain the quality of its services, Client Services was forced to accept no more than 100 new clients each month. Prompt referrals to other GMHC services and outside agencies are helping those on Client Services waiting lists find alternate sources of support.

Even with these new and unwelcome limits, the numbers are staggering. Client Services staff completed more than 1,400 intake interviews this year. More than 3,500 men, women and children with HIV illness are now taking advantage of our client services, which include:

- **Getting help to people with AIDS in homes, in hospitals and in transition.** GMHC buddies, crisis intervention workers and crisis management partners helped more than 900 clients cope with their AIDS diagnoses and the demands of daily life — everything from grocery shopping to financial planning, advice on family matters and walking the dog. Five new volunteer teams were created this year, including a Filipino team. In July, our new "Bridges" Project began to offer short-term help to people with AIDS who have recently returned home after a period of hospitalization.
- **Replacing isolation with support.** GMHC ran 44 different support and therapy groups this year to cut through the isolation that is one of the most common side-effects of an AIDS diagnosis. Groups included those for people with HIV illness, their care partners and the recently bereaved, and special groups for women, Spanish speakers, and clients in recovery from substance use. A new series of on-site Alcoholics Anonymous meetings is also helping clients in recovery to stay sober.
- **Fighting financial hardship.** Our financial advocates performed over 1,000 financial assessments, held 500 seminars and forums for GMHC clients, fought for policy changes in numerous city agencies, and helped clients to obtain benefits such as public assistance, Social Security and Medicaid. GMHC also distributed almost $150,000 in emergency grants to help clients eat, pay rent and meet utility bills.
- **Increasing services to families with AIDS.** Our Child Life Program provided baby-sitting, field trips and other support to more than 100 families with HIV this year. The program has created an on-site playroom for the 300 children it serves, extended child care to three days a week, and begun a series of meetings for parents on issues such as disclosing their HIV status to their children.
- **Providing meals and recreation.** GMHC's Nutrition Program served over 40,000 free hot meals to people with HIV-related illnesses this year. Volunteers and newly-hired staff nutritionists provided hundreds of individual nutritional counseling sessions and produced educational materials on nutrition and HIV in English and Spanish.



Through our Recreation Program, over 2,500 clients took advantage of GMHC's classes, outings, theater tickets and in-house chiropractic, massage and acupuncture services.

■ **Forging connections for clients whose needs cannot be met by GMHC alone.** Our case managers help 120 clients a month take advantage of GMHC's services and those provided by other community-based AIDS organizations. Doubling in size this year alone, the case management team now includes Spanish and English speakers with expertise in women's and children's issues, psychiatric concerns and drug counseling.

■ **Training volunteers and staff to work more effectively.** More than 1,300 new volunteers took part in GMHC's four-day training sessions this year. Client Services also offered staff and volunteers additional trainings on issues such as suicide prevention, substance use, tuberculosis and HIV-related violence.

LEGAL SERVICES helps people answer the many legal questions that come with HIV infection. Staff lawyers and legal advocates work with 600 volunteer attorneys to offer people with HIV advice, draw up documents for them, and represent them in negotiations, hearings and in court.

Wills, once the most important legal issue for GMHC's clients, are now only one of many. The department doubled in size this year, working to help nearly 1,400 clients with legal matters including:

■ **Reaching out to immigrants with HIV** through a new project that brings attorneys to GMHC and four other locations in Queens, Brooklyn and Manhattan.

■ **Helping attorneys all over the state** through a first-of-its-kind legal back-up center that holds trainings, provides technical assistance, and answers a wide range of questions about HIV and the law.

■ **Providing over 650 clients with legal documents** to help them plan for the future, including wills, health care proxies and powers of attorney.

■ **Working with the Bronx AIDS Services Project** to start a legal services department within that organization and to provide technical support to hospitals and other AIDS service providers in the Bronx.

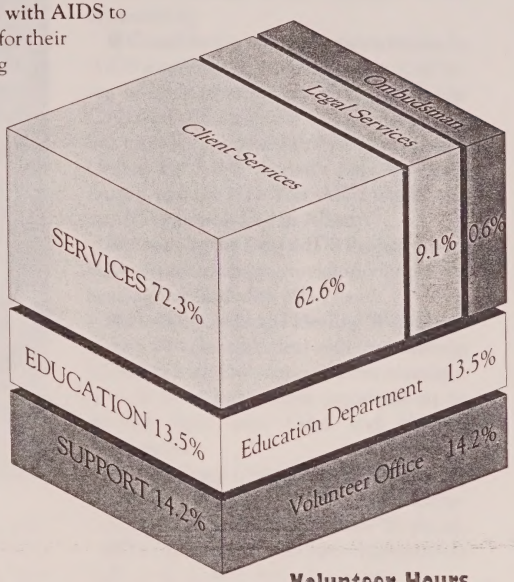
■ **Assisting with insurance problems,** representing clients in insurance disputes and holding weekly clinics and monthly forums to guide people with HIV through the growing complexities of insurance coverage.

■ **Opposing housing and employment discrimination.**

■ **Helping parents with AIDS** to arrange guardianship for their children, and handling disputes over child custody or visitation rights.

■ **Negotiating with landlords, creditors and the I.R.S.** on behalf of hundreds of clients whose medical condition makes it impossible for them to manage their debts.

■ **Recruiting and training volunteer attorneys,** and successfully seeking the involvement of major law firms on a *pro bono* basis.



Volunteer Hours
1991-1992
Total Hours: 150,273

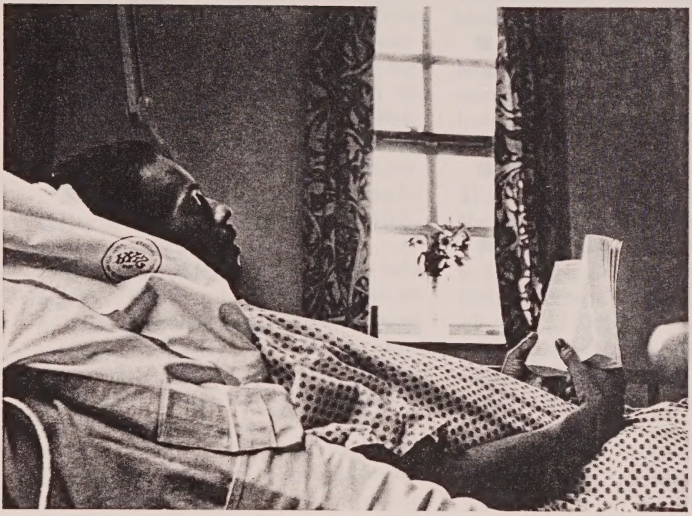
THE OFFICE OF THE OMBUDSMAN is where people with HIV illness and their care partners can get help accessing health care — hospital care, clinic visits, treatment in doctors' offices or at home. When an insurer refuses to reimburse a client or a doctor discharges patients from the hospital before they are well, the Ombudsman's Office works to resolve the problem.

The Ombudsman's Office also advocates for the growing numbers of New Yorkers who might not otherwise have a place to turn: homeless people; women who have AIDS and are caring for other family members who are sick; prisoners; or homeless people without doctors or family support. Finding the common trends among many individual complaints, the Ombudsman presses hospitals, City and State agencies and insurance companies to improve service delivery for people with HIV.

The Ombudsman's Office handled 1,631 cases this year that involved:

■ **Improving hospital care.** Many people with HIV-related illnesses are being forced to

wait for weeks or months for appointments in infectious disease clinics throughout the city. Those in hospital beds sometimes find themselves without even basic amenities: sheets, blankets or a nurse.



■ **Speeding up delays in housing programs.** Approximately 20% of GMHC's clients are homeless or live in shelters or SRO hotels that are not medically appropriate for people with HIV infection.

■ **Increasing and improving long-term care.** Though both cheaper and more appropriate for many people with AIDS than hospital beds, long-term care facilities remain virtually non-existent in New York City. GMHC and other advocates are fighting for more long-term beds, and for better care in the few facilities that do exist.

■ **Challenging insurer negligence.** People with HIV are finding it increasingly difficult to get reimbursements for treatments and medical equipment prescribed by their doctors, particularly when those treatments are considered preventive or experimental.

THE VOLUNTEER OFFICE recruits, interviews and orients all volunteers, and works to make sure that both their needs and those of GMHC are being met. Assigning volunteers to the departments that can use them best, the Volunteer Office is a crucial link between GMHC's staff and our most valuable resource. Increasingly, the Office is also the motor behind GMHC's grass-roots campaigns to raise AIDS awareness statewide.

The office's achievements this year include:

■ **Recruiting, interviewing and orienting 1,300 new volunteers,** and redirecting experienced volunteers to new positions in the organization.

■ **Coordinating volunteer participation** in AIDS awareness events such as the "Gathering of Remembrance and Renewal" in the Cathedral of St. John the Divine, our sweeping, citywide condom distribution campaign, United for AIDS Action's rally in Times Square, and the New York AIDS Coalition's AIDS Awareness Day in Albany.

■ **Assisting the Deaf AIDS Project** recruit and train volunteers to provide services for the hearing-impaired with HIV.

■ **Holding Grief and Healing Workshops** to help 84 volunteers deal with their feelings of grief in a safe and supportive environment, as well as training other organizations to develop their own Grief and Healing Workshops.

■ **Organizing GMHC's presence** and the distribution of condoms and safer sex information during Lesbian and Gay Pride Weekend.

■ **Producing volunteer appreciation events** such as the annual Moveable Feast.

Donate Because AIDS is Everyone's Fight

With a very limited endowment fund, GMHC is forced every year to confront hard financial realities. We have nowhere near the money we need to get hundreds of men, women and children off our waiting lists and into our programs. Only the generous gifts of several individuals came between GMHC and a cash deficit this year.

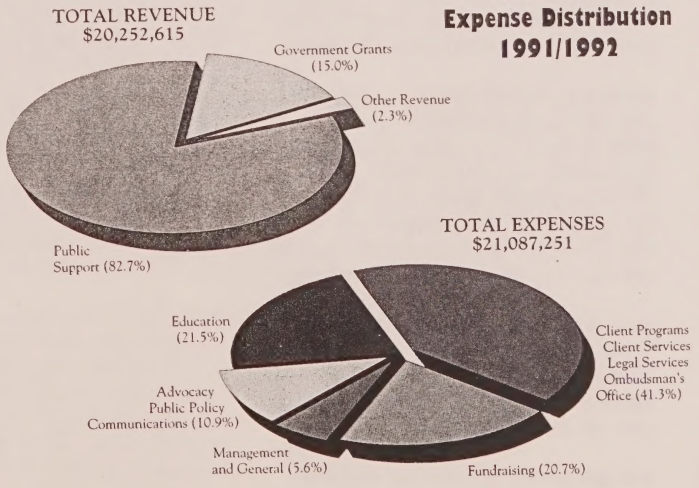
For 11 years, GMHC has depended on individuals to help us make the most of what we have. We began our Hotline on the answering service of a volunteer. Our six-story headquarters, paid for by a special fundraising drive, was furnished entirely through donated furniture and supplies. Today we still rely overwhelmingly on community support: hundreds of thousands of individual donors; corporations who sponsor teams for our special events; foundations who support our special programs; and restaurants and other businesses who contribute money, space and services to help us hold fundraisers and deliver services.

Next year we will have to work to reach out to new donors and ask old ones for more. The longer we wait to act, the more lives will be lost. Closing your mind to AIDS — or your checkbook — can only keep the epidemic growing.

THE DEVELOPMENT DEPARTMENT is GMHC's link to the individuals, corporations and foundations that power our fight. Constantly searching for new ways for GMHC to rally financial support, the Development Department realized $16.8 million in net income this year, an increase of 11% over last fiscal year. The department's fundraising accomplishments this year included:

- **AIDS Walk New York** — the world's most successful AIDS fundraising event. Twenty thousand walkers, backed by a quarter of a million sponsors, walked through driving rain on May 31, 1992 to raise $4.7 million. GMHCgave 15% of the net proceeds to other AIDS organizations, distributed largely through the New York City AIDS Fund.
- **A $1 million gift from entertainment entrepreneur David Geffen,** the largest individual donation ever received by GMHC (for fiscal year 1992-93).
- **A $250,000 challenge grant from the Tisch family,** the largest single gift in GMHC's history at the time of its donation.
- **"Friends for Life," the annual giving program** GMHC launched with underwriting from Board member Judith Peabody and her husband Samuel, which raised nearly $1.4 million this year from 581 contributors.
- **The second annual GMHC Dance-A-Thon** on November 30, 1991, in which 7,800 New Yorkers of all ages raised $1.6 million.
- **Direct mail,** which raised a record $4 million in individual contributions, and GMHC's Benefactors plan for monthly giving which raised $545,000.
- **"Circus For Life,"** at Madison Square Garden on March 27, 1992. Ringling Brothers & Barnum and Bailey Circus and a crowd of 15,000 came together to raise $1.1 million and commemorate GMHC's first major fundraiser, the 1983 Circus.
- **"Partners in Planning,"** GMHC's new planned giving program. Launched this year, the program assists donors in their financial management and estate planning, and raised over $350,000 in donated assets and charitable trusts.

Revenue and Expense Distribution 1991/1992



Educate to Fight Fear with Facts

From the start, AIDS was accompanied by an epidemic of fear and denial. Elected officials looked at the sex and drug use linked to AIDS and saw controversies that were too hot to handle. Mainstream society looked at the gay men and drug users who were the first wave of the epidemic and saw a disease that was safely "on the margins." And while people looked away, the margins moved inward. AIDS moved closer. Today, the majority of Americans know a friend, a colleague or a relative with HIV.

Why is HIV still spreading? Years after we've learned how to stop the virus, we have yet to see an effective national AIDS prevention effort. Instead, the government offers us vague euphemisms and unrealistic "Just Say No" campaigns. Thousands of sexually active gay men have never seen a condom, much less used one. Millions of Americans of every sexual orientation, from rural areas to inner cities, have yet to receive the information that can save their lives.

How exactly do you put on a condom? What can you do once you test HIV-positive? GMHC educators have been fielding those kinds of questions for years, and answering them in language their audiences can understand. Our workshops to keep sex safe and satisfying draw crowds: to date, more than 55,000 participants have attended. Our early AIDS information pamphlets have been joined by new titles as the epidemic has expanded: *Women Need to Know About AIDS*, *The Safer Sex Condom Guide for Men and Women*, *¿Qué es el SIDA?* Our materials don't mince words or put fig leaves over the parts of the pictures people need to see to understand. It can be embarrassing to talk frankly about unsafe sex or drug use. But you can't die from embarrassment.

Our materials don't mince words or put fig leaves over the parts of the pictures people need to see to understand.

The infections people with AIDS *do* die from — and how to prevent and treat them — are the focus of our Medical Information Program. Thousands of people with AIDS and their health care providers attend our community forums on HIV and receive our newsletter on the latest scientific and medical advances in AIDS treatment. There is far more treatment education to do: Many women, for example, are sent home undiagnosed by doctors who don't recognize their symptoms. And last year alone, 20,000 Americans were diagnosed with an AIDS-related pneumonia that is often preventable.

GMHC's EDUCATION DEPARTMENT is the largest non-governmental distributor of AIDS education materials in the world. We put out publications and videos, produce a weekly cable television show, conduct HIV prevention workshops and distribute information in bars and clubs, at health fairs and on city streets.

This year, the Education Department's strategies included:

- **Fighting fear with facts.** The GMHC Hotline, staffed by trained volunteers, answered a record 83,000 calls this year, a 29% increase over last year. The A-Team, our in-house, drop-in peer counseling group, offered counseling to almost 1,300 individuals, a 15% increase.
- **Reaching out in communities of color.** GMHC's new strategies include a safer sex play in Spanish, the "What's In it 4 Me? A Safer Sex Thang" workshop by and for African-American gay men, and GMHC's "House of Latex" to bring the safer sex message to gay youth of color.
- **Improving education to adolescents.** This year GMHC produced and released *It Is What It Is*, an hour-long video designed for high school and college audiences that addresses teen sexual identity, homophobia and safer sex.
- **Getting treatment information to people who need it.** 175,000 copies of *Treatment Issues*, our newsletter on the latest in AIDS treatment and research, were published and mailed to physicians and people with HIV worldwide. A special *Treatment Issues* was devoted this year to women with HIV, who continue to die faster and get less care than men.
- **Providing practical advice on safer sex.** Over 2,000 people attended our workshops — "Men Meeting Men," "Eroticizing Safer Sex," and "Sex, Dating and Intimacy" — to help gay and bisexual men incorporate safer sex into their relationships.
- **Making condoms and information free and easily available.** GMHC distributed over

1.5 million condoms this year — more than were distributed by the City of New York — and gave out more than 983,000 pieces of educational literature.

■ **Creating long-term AIDS prevention programs.** GMHC's "Keep It Up!" program is the first of its kind to help gay and bisexual men maintain lifesaving sexual behavior. GMHC, with the San Francisco AIDS Foundation, is now assisting organizations nationwide to provide similar support.

■ **Speaking from experience.** People with AIDS, Board members, volunteers and staff from our Speakers' Bureau addressed nearly 12,000 members of community groups on issues as varied as "AIDS 101," treatment developments and volunteer opportunities.

■ **Bringing education into the workplace.** GMHC's AIDS Professional Education Program trained over 3,300 city mental health workers on HIV concerns. Our Employer Education program made 89 presentations to over 1,300 managers, human resource personnel and line staff, an increase of 205% over last year.

THE LESBIAN AIDS PROJECT was started this year to create education, advocacy and support services responsive to the needs of lesbians living with HIV. Equally important, LAP's existence makes it clear that women who have sex with women, however they identify themselves, are at risk for and living with HIV illness.

LAP began in April 1992, after a series of meetings between GMHC and an advisory group made up of lesbians with HIV and lesbians working in AIDS. In keeping with GMHC's mission statement, which makes an explicit commitment to serving New York's gay and lesbian communities, LAP is creating support groups, educational materials, and a network of community advocates to help women who, for the last decade, have been ignored by the Centers for Disease Control, AIDS researchers, health care providers and the majority of AIDS service organizations.

Soon to produce GMHC's first lesbian safer sex kits, LAP has begun its research with a Lesbian and Bisexual Women's sex survey. More than 1,000 women have already responded to this first-of-its-kind survey, which continues to be distributed through community lesbian organizations, to sex workers, in prisons and in lesbian bars. Other ongoing projects include a young lesbians outreach initiative, a program for lesbians in or recently released from prison, a LAP newsletter and the creation of a legal training to address specific issues confronting lesbians with HIV.

Fight to Force the Government to Act

Services can help us manage the AIDS crisis, but only government action can end it. We cannot plug the gap when new funding for AIDS research does not even keep pace with inflation, or when the President trumpets the passage of an AIDS Housing Opportunities Act and then cynically asks — not once, but twice — that it receive no funding. We cannot force Congress and the President to fund AIDS disaster relief fully, or to end the discrimination which stigmatizes Americans with AIDS and keeps HIV-infected foreigners out of the country. No community-based organization can do the government's job.

Most of the problems in AIDS policy return to a single fact: The people least affected by the epidemic make most of the decisions. GMHC is working in every way it can to make sure that people with HIV have a place at the table and a voice in the political process. We lobby in Albany and Washington and launch postcard and telephone and grass-roots organizing campaigns. We poll the public, file suits in the courts, work behind the scenes and through the media to get the politicians a ten-year-old message they don't seem to have heard yet: *We are not giving up. We are not going away. We are people with AIDS and people who care about them and we cannot live with another decade of no vision, no funding and no leadership in the fight against AIDS.*

This year, fiscally one of New York's worst, THE PUBLIC POLICY DEPARTMENT worked in coalition with other AIDS advocates to beat back virtually all cuts in State and City AIDS programs. Testifying at hearings, coordinating coalition efforts, creating advocacy strategies and confronting sluggish government bureaucracies, members of the department led the campaign to demand:

- **Accessible Health Insurance.** GMHC and other health organizations deluged State legislators with postcards, phone calls and demands for meetings to protest insurers' discrimination against New Yorkers with AIDS and other disabilities. On July 1, 1992, New York passed landmark legislation requiring insurers to offer open enrollment to all individuals and small businesses, and to stop charging higher premiums to businesses they deemed "risky."
- **Presidential Leadership.** GMHC spearheaded United For AIDS Action — the largest coalition of AIDS and health organizations in history — to force both political parties to address the issue of AIDS. UAA's 480-member organizations drafted a five-point platform and sent it to all presidential candidates, led voter registration drives, and met with presidential candidate Bill Clinton. GMHC and other UAA members rallied 25,000 people in Times Square during the Democratic Convention, and went to Houston to speak out during the Republican Convention.
- **Leadership and funding in New York.** Working with the New York AIDS Coalition, GMHC brought over 1,200 people with HIV and their advocates up to the State Capitol this year. In the middle of a recession and a fierce debate over how scarce resources are

allocated, GMHC helped win a $4 million increase in State funding to community-based AIDS organizations serving people of color and an 11% increase in New York City spending on AIDS.

■ **Faster and better AIDS research.** The handful of drugs now approved to fight AIDS and the infections it causes are expensive and inadequate. GMHC's Policy Department is working with other AIDS activists and the federal government to streamline and improve clinical trials for new drugs, with particular attention to infections and treatments for women with HIV.

■ **Education for adolescents.** After working successfully to make HIV education and condoms available in New York City schools, GMHC led the fight to prevent a parental "opt-out" clause from crippling that condom availability program. We are now working with the State Advisory Committee to draft and implement a new AIDS curriculum from grades K through six.

■ **Clean needles and new services for intravenous drug users.** GMHC led the effort to unite health care providers and advocates in support of a comprehensive risk reduction strategy for drug users, including community-based needle exchange programs.

■ **More attention to women's issues.** GMHC is working to reform the official definition of AIDS which ignores infections common to women and drug users with HIV and is challenging the Social Security system which locks many people disabled by HIV out of government benefits.

■ **Disaster Relief.** The Ryan White CARE Act, though funded by Congress at less than a third of the recommended amount, will provide New York City with $35 million in AIDS disaster relief in 1992. GMHC, an active member of the Planning Council that decides how those funds are used, is pushing for increased funding of the bill next year.

THE COMMUNICATIONS DEPARTMENT, nationally recognized as a consistent and authoritative source of AIDS information, creates hard-hitting campaigns to reach the press, politicians and public who shape America's response to AIDS. In addition to this Annual Report, several other Communications publications keep our volunteers, donors and staff informed about AIDS and GMHC: *The Volunteer*, a bimonthly newsletter with a circulation of 70,000, and the monthly, two-page *News From GMHC*.

This year, Communications was busy:

■ **Waging advocacy campaigns** that combined newspaper advertisements, paid radio spots and press conferences to raise awareness on issues such as AIDS education, insurance reform and presidential inaction.

■ **Getting people with HIV seen and heard** through *The Volunteer's* "Living With AIDS" column and our VOICES project, which connects clients with members of the media and others interested in a first-hand perspective on AIDS issues.

■ **Producing a *State of AIDS Report*** evaluating New York's response to the epidemic and releasing it at press conferences in Albany and New York City just before Governor Cuomo's State of the State Address.

■ **Polling the public on AIDS education,** and challenging all levels of government to act on the findings. Polls GMHC commissioned from the Roper Organization have consistently found the public to be anxious for more and better AIDS leadership and education.

■ **Holding press conferences and briefings** on issues such as the CDC's AIDS education campaign, condom availablility in New York City public schools and, GMHC's new Immigrants with HIV Project.

■ **Working with newspaper editors and television producers** across the country to improve coverage on a wide variety of AIDS issues.

We wish to acknowledge the leadership of the following government agencies, whose financial support of GMHC allows us to continue the fight against AIDS.

New York State AIDS Institute
New York City Department of Health
Medical and Health Research Association — Ryan White CARE Bill
New York City Human Resources Administration
Interest on Lawyers Account
New York City Department of Mental Health and Mental Retardation
New York State Bureau of Nutrition
United States Public Health Service
New York State Legislative Add-on
Federal Emergency Management Agency
New York State Department of Social Services

Unite to Make the Most of Limited Resources

GMHC is not fighting alone. Every day we work with dozens of other community organizations to strengthen and broaden the network of care for people with HIV. We are joining forces to shatter the political silence on AIDS, and using private funds to demand greater public commitment to ending the epidemic. Joining organizations as diverse as the March of Dimes, Black Leadership Commission on AIDS and United Auto Workers, we filled Times Square during the Democratic Convention. We were in Houston at the Republican Convention, working with organizations like the National Gay and Lesbian Task Force, the Log Cabin Republican Club and Mothers' Voices to force proponents of "family values" to recognize how many in the American family — a family which includes gay men, lesbians and single mothers — are sick.

We were in Houston to force proponents of "family values" to recognize how many in the family are sick.

Together, we are also breaking down barriers to service delivery. GMHC's Fellowship Program, completed this year, brought 26 AIDS professionals from as close as the Bronx and as far as California to GMHC for four-month-long training sessions. Whether by helping the Minority Task Force on AIDS design an intake procedure or by training AIDS education staff and volunteers in the New York City school system, we are reaching New Yorkers not able to come to GMHC. With Ryan White disaster relief funds, we are creating new partnerships to get help to New Yorkers who are under-served and ignored — immigrants with HIV, for example, or lesbians, or people with HIV who receive mental health services but little or no AIDS care.

GMHC staff offered thousands of hours of technical assistance to AIDS organizations, schools and universities and other human service organizations this year. We put our expertise and resources toward helping others with issues as varied as fundraising, program development, nutritional trainings and computer support.

We are creating coalitions, mobilizing a movement, and proving — again and again — that the fight against AIDS is one all of us are determined to win.

The organizations GMHC provided technical assistance to this year include:

ACT UP
AIDS Center of Queens County
AIDS Related Community Services
AIDS Service Center of Lower Manhattan
AIDS Treatment and Data Network
Alliance for the Arts
Alianza Domínicana
AmFAR
ASPIRA
Betances Medical Services
Black Leadership Commission on AIDS
Body Positive
Brooklyn AIDS Task Force
Bronx AIDS Services
Cancer Care
Citizen's Advice Bureau
Commission on Human Rights
AIDS Division
Community Health Network
Correctional Association
Daytop Village
Federation of Parents and Friends of Lesbians and Gays
First Unitarian Church
Food for Survival
Fortune Society
Gay Men of African Descent
God's Love, We Deliver
Hispanic AIDS Forum
Jewish Board of Family & Children's Services
Legal Action Center
Methodist Hospital
Minority Task Force on AIDS
Momentum Project
Mothers' Voices
New York AIDS Coalition
New York City Public Schools
SAGE
SHARE
St. Francis of Assisi AIDS Ministry
Stand Up Harlem
Staten Island AIDS Task Force
Upper Room AIDS Ministry
Women's Prison Program

LEW KATOFF, *Staff Member*

"I HAVE STRUGGLED A LOT WITH

why I've become a long-term survivor. Why, since my first bout of pneumonia in '86, was I able to go back to work so quickly? Why haven't I gotten a second major illness or opportunistic infection? I think the hardest issue to deal with is the loneliness of the long distance runner. So many of the people I've been closest to in my life, who I'd have gone to for support, are no longer there. My best friend since I was 12, dozens of people I've worked with — they were all diagnosed after I was, and they've all died. In addition to all the sadness and loss, I feel guilty. I can care for my friends, I can support them. But whatever secret I have, there's no way I can know what it is or how to give it to them.

"I always worked to keep AIDS from taking over my life. I was an obnoxious patient when I needed to be. I refused to wear a hospital gown. I insisted on taking showers rather than sponge baths, and on shaving every morning. Of course, I was lucky: Working at GMHC, I never had that sense of isolation and abandonment that so many people get when they are diagnosed. My boss came and visited me in the hospital. Someone I worked with helped get me into an experimental drug trial. I had a supportive lover who still walks in the AIDS Walk and volunteers in the Education Department. And I didn't have to hide my illness at work. Everyone probably knew, anyway, because being in the hospital was the only thing that would have kept me from the volunteer Team Leader meeting I was supposed to attend the day I was diagnosed.

"'I don't know why these volunteer teams work, but they do,' one of my colleagues told me when I first took the job supervising the teams of buddies and crisis intervention volunteers. She was right; by ordinary standards it didn't make any sense. These volunteers were people with no mental health counseling background. They had busy jobs and busy lives. I loved to watch them performing these acts of courage and nobility: meeting clients in the emergency room, arguing with doctors who were discharging people inappropriately, helping people figure out where to get groceries, or how to avoid suicide. I think AIDS volunteerism brings out the worst feelings, but the best actions.

"The stress can make it difficult to work at GMHC when you have AIDS. As the one responsible for 50 different volunteer teams, and later as the Director of Client Services, I knew some people wanted me to be a daddy instead of someone who was sick himself. When I'd be working hard or feeling sick, I could see my co-workers getting upset. Once, when I had a bad

pancreatic reaction to a drug and lost a lot of weight very quickly, the executive director called me in and told me to take three weeks off. I didn't. When you're not sure how much time you have left, you learn how to make your own choices.

"I'm still learning. I'm constantly making choices about treatments — right now, I'm on six different medications. I've been in three clinical trials for drugs that weren't approved yet. I went to France for one of them after I saw a poster at a conference. I sought out specialists, learned what to cut from my diet, and jogged until a neuromuscular disorder made that impossible. It's getting harder and harder for me to walk up stairs and inclines, but I still go to the gym three mornings a week. Recently, I've decided it's okay to take a cab instead of a subway if that leaves me more energy to exercise.

"At work I'm helping others make the most of limited resources, coordinating the technical assistance GMHC offers to dozens of smaller AIDS organizations. I also went to last year's International AIDS Conference to present the results of my research on 53 long-term survivors of AIDS. Just about the only thing they all had in common was that they had a doctor they felt comfortable talking with — and challenging.

"I'm proud of that study, but I'm not satisfied. I keep hoping that if I talk to enough people, crunch enough data, read enough transcripts enough times, I'll find some answer. Not for the world, but for all the people in my life who are ill."

"I was an obnoxious patient when I needed to be."

LEONARD LAMBERT, *Volunteer*

"I BECAME A GMHC VOLUNTEER

by coincidence. I wanted to run groups for gay men who had recently broken up with their lovers. Someone told me there was a place out there called 'gay men's something,' so I called the operator and got the number. My GMHC interviewer was inspiring — smart, professional, insightful and African American. It made a deep impression on me, seeing another African American man who was working to take action against AIDS. When GMHC asked if I'd consider conducting intake interviews, I agreed to give it a try.

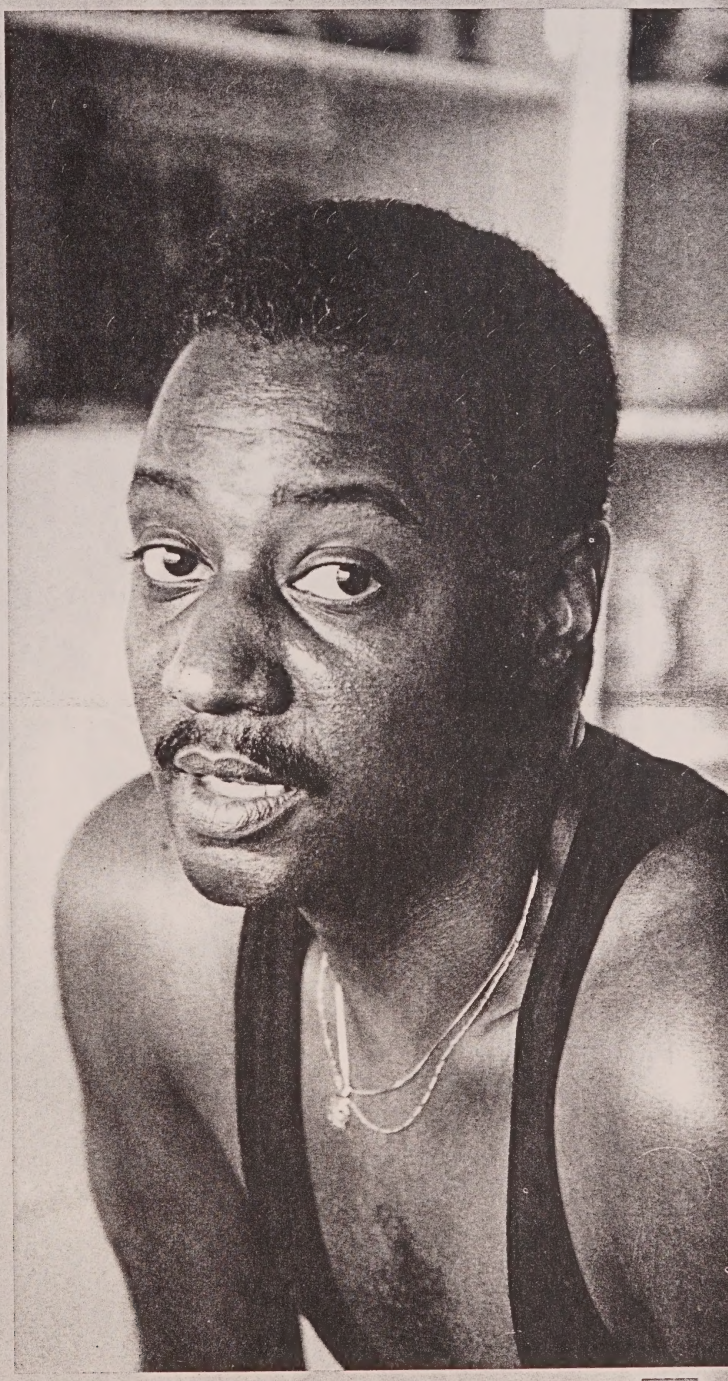
"I work in psychiatry. I'd had five years of experience working at Harlem Hospital. But the three years I spent doing intakes at GMHC were definitely full of new challenges. Clients would start to talk about their diagnosis, and all their questions just mushroomed out from there: 'What should I do about money?', 'What if my lover gets sick too?', 'What about my fear of death?', 'Who can I trust at work?' Some people seemed to bring all this anger to the interview, challenging me: 'You want to help me? You're going to have to prove that you can.' Other people brought boxes of tissues, and it was easy to understand why. Talking to so many people about dying prompted me to start thinking about it myself. 'Couldn't I be sitting in their chair?' I kept asking myself. I wanted to bring that sensitivity to the work I was doing. But it took me a while to get over the fear, to learn how not to hide behind the questions on the intake form.

"I was working full-time, so I did interviews when I could — late in the evening, on Sunday mornings. A lot of the hospitals asked me to put on a mask and gown before going into a room, and I would feel bad because the patient could only see my eyes. Sometimes I'd go to do an interview and find clients lying sick in their apartments, with no one around. As far as I was concerned, 'intake' could also mean going to the store to get someone dinner, or calling a day later to see how someone was doing. I stretched the boundaries when I felt like I had to.

"I was also confronted with my own limitations. I remember visiting one client and finding his Southern mother in the doorway. The situation made me uncomfortable: the apartment was dark, the mother seemed anxious and on edge. I went in and looked at the client, who was lying motionless in a room with no windows, and I remember feeling totally overwhelmed. I explained to the mother that her son needed immediate medical help. Then I asked, 'Mother, how are you doing?' and stood there and watched this woman reach for me. Not in anger, but breaking down in tears. Whether you're a Southern white woman or an African-American man of Southern background, the tragedy of AIDS evokes the same feelings.

"I found a lot of validation and acceptance at GMHC. I've worked at places where I was hired to do something and I got to do everything *but* that. At GMHC you actually do what you came to do. You take care of people.

"I love GMHC for taking care of so many people and situations. I hate the fact that the organization, even as it grows so quickly, hasn't been able to put itself out of business or do all that has to be done. I accept the challenge of dealing with all the changes by staying. I know I can speak out on anything I don't feel comfortable with here. And I've often reflected on my first impression when I came for my interview at GMHC. If what I'm doing encourages others to join the battle against AIDS, then that is one big accomplishment."



SHERRI TERRIZZI, *Client*

"I'M NOT DYING OF AIDS, I'M

living with it. I hate that cliché. But it's true, I *am* living. There are days when I get so tired I almost have to crawl up the stairs, and I don't have everything in place: I still have no one to leave my kids with when I die. But they think I'm bionic anyway. And I figure I must have some life left, because I have faith that before my time's up those things will be set in order. The Lord is my strength and my constant companion. At home and in my schoolwork at the College of Staten Island, He gives me the will to go on.

"I'm still Sherri, I'm not anybody different or dirty. But some people can make you feel so unclean when you are HIV-positive. I've had so-called close friends reject me, refusing to visit the house or setting aside a 'special glass' for me to use. I still look to see if people pull away after I shake their hand. Nobody deserves that.

"I was even scared to tell my kids, though they must have known something was wrong. Right after I found out I had the virus I had to go pick my littlest daughter up from nursery school, and my eyes were practically swollen shut from crying. I kept getting these unbearable headaches, and my glands were so swollen I couldn't turn my head. After two months, I finally told them, 'Listen, be quiet. Mom just found out she has cancer.' I couldn't say the 'A' word. I just couldn't say it. My kids are HIV-negative, they're fine. But my greatest fear is people in the neighborhood finding out about me and deciding not to let their children come over to play any more.

"I needed to confide in someone who wouldn't run away from me. I got involved with Staten Island AIDS Task Force, and went into a women's support group. They put me in touch with the New York City Division of AIDS Services, though that didn't always make things easier. It was like hit and miss: every time I went to the check cashing place, they'd changed the amount of my benefits without giving me any notification. I was told I couldn't stay on the program that helped pay my tuition and carfare. 'School's not allowed,' they said. I said, 'I was in college when I found out about this, so why should I quit and die?' 'Well, you're going to die anyway,' the supervisor told me. Her name was Hope, but I found her hopeless.

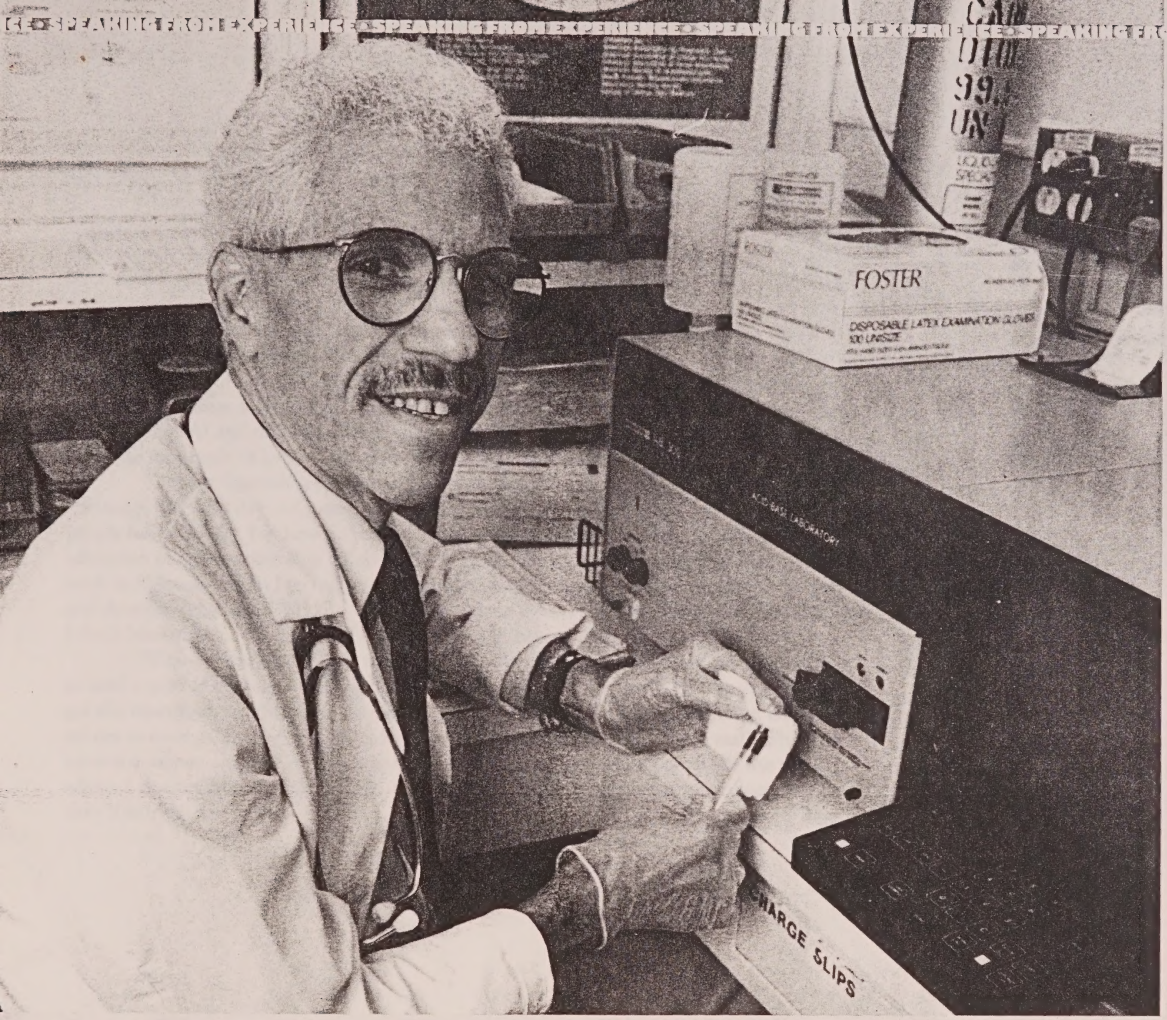
"GMHC helped me straighten that out, and supplied two buddies for me. It was hard to adjust to someone else helping me out — before I had HIV, I never let anyone touch my house. But I was getting so tired that I felt overwhelmed by both school and housework. I didn't feel right making my daughters cook and clean. Michael, my first buddy, came over and helped three times a week. Now I have Steven, who comes on Friday nights and is a tremendous help. In addition to chores, he talks to me, and I need that, too.

"I come to GMHC because people accept me here. And I can't say enough good things about GMHC's Child Life Program for supporting my kids. We go on as many GMHC trips as we can: the planetarium, the petting zoo, the circus and Sesame Place. My two oldest daughters especially need relief from the tension. They know I have AIDS, but they can't tell anyone. My oldest girl is afraid I'll go public — she's always telling me how she doesn't want me to go on television.

"I'm hiding less and less. I go to women's shelters and hospitals for the Task Force, visiting and handing out condoms and literature. I've designed a research project on women and AIDS, and I'm starting to speak at public health forums and local high schools. People always tell me I don't look like I'm sick and I say that's the point: There's no 'look' to AIDS.

"At my own school, I'm handling the pressure. My grade-point average is high, and I've won two scholarships. After I graduate, I'm planning to go on with my studies, get my Masters in Social Work and help people with AIDS. I figure I know just how they feel."

"People always tell me I don't look like I'm sick and I say that's the point: There's no 'look' to AIDS."



BERNIE GONZALEZ, *Volunteer*

"OF COURSE I'D HEARD ABOUT

GMHC for years. In the early '80s I was working as a volunteer nurse at the Community Health Project. It was my Wednesday night routine: get out the penicillin, give shots, do blood tests and counseling. But people started coming in with new symptoms — night sweats, weight loss, diarrhea. These people not only needed to see doctors, they needed continuity of care and legal help. This was before CHP was hooked up with a hospital, before there were any AIDS drugs. All we could do was refer people to GMHC and a very few other places.

"My decision to get more directly involved with the organization was based on a single reason: I wanted to do something for Latinos and blacks. People were hearing about it all the time — 'el SIDA, el SIDA, el SIDA'— but that didn't mean they felt comfortable coming for help. Don't forget, our name is GMHC. I don't have a problem with that, and I don't ever want to see the name changed. But where I grew up, in East Harlem, we didn't

have such a thing as the gay community. You might be playing around with men, but that didn't mean you were 'gay.' Some people still had wives and children.

"I remember so many Central and South American and Cuban men — kids, really — who were going wild in the early '80s. They were in New York! There were no government crackdowns, no secret police, no *comités*! They were having the sexual time of their lives, and they were dying. A lot of them were also here illegally, and that made them suspicious of going to organizations and filling out applications.

"My friends and I had our own suspicions about GMHC, thinking it was only for white gay men from Chelsea. When I started volunteering, I think there was only one Latino on the Board. But I told my friends what I told myself: You can't fight from the outside. If you want to change something, be part of the process. I co-wrote an information pamphlet, *¿Qué es el SIDA?* and translated many others. And when GMHC began the education programs for people of color, I felt they had made a commitment.

"Getting Spanish speaking volunteers to make the needed commitment is another challenge. Where I live in Queens there are so many gay bars for Latinos now, so many young people full of energy, but how do you recruit and retain them? I'm working with the Latino education program to develop volunteer trainings in Spanish. Every time I go out — when I work in hospitals, when I go to give presentations at colleges — I always ask people to come and do something with GMHC. 'Yes, yes,' everyone always says, but a lot fewer show up, and I don't blame them. From a lot of neighborhoods, Chelsea's a long way away.

"How do you break down those barriers? At one of the hospitals I work in, we had to send a mother a telegram telling her that her daughter was critically ill. By the time she got the news four days later, her daughter had died of AIDS. It turns out Western Union refuses to even go where this mother lives — they'd put the telegram in the mail. She didn't have any money, or any idea where to bury her daughter. I could only give her the same advice I give my friends who are sick: Call GMHC. If they don't have the answer, then they'll help you try to find one."

"You can't fight from the outside."

RANDY WOJCAK, *Volunteer, Client and Board Member*

"I WAS AT A PARTY THE OTHER

night where there was a palm reader. 'Why don't you go over?' everyone kept asking, but I was scared to death. I didn't want to hear what she was going to say. Finally, I go over to her and she looks at my hand and starts telling me what a strong lifeline I have. I'm wanting to be real positive while she's telling me this, but I'm thinking, 'You must not be very good.' I told her about my diagnosis and she just looked at me and said, 'So? What difference does that make?' She had a point.

"Living with AIDS means living with uncertainty.

"AIDS changed my life long before I was HIV-infected. I remember going to one of GMHC's education forums in 1985, just after I'd moved to New York, and listening to people talk openly about sex. I'd just never heard that before. I grew up in Del City, Oklahoma, where sex was something you only whispered about. Safer sex was something for people in New York and California. But sitting and listening to the doctor who was leading the session, I could feel this tremendous barrier coming down. It was such a relief to hear people joking and talking frankly about what you needed to do to keep from getting HIV.

"I became a GMHC volunteer myself. During the day, I'd work as the Director of

Management Information Systems at a high-power, straight-laced, company. At night I'd go to colleges, local lesbian and gay groups, or community centers, and teach people about how to protect themselves. Or I'd work on the Hotline, answering questions that would have left me speechless a few months before: 'How can you use condoms for oral sex?', 'How can I get the man I am dating to wear a condom?' Back then, a thin little referral book had all the available information. Today, there are volumes. I've spent the last two years developing a computer system to help us pull all that information up quickly.

"I talked a lot about AIDS then, but I didn't think about it in personal terms. I was sure I was HIV-negative. I was healthy — hadn't been to a doctor since I was 18. I got tested anyway. When the doctor told me I was positive, I couldn't stop crying.

"I got on the wrong train to go home, and got off at the wrong stop. I walked in front of oncoming traffic. I suddenly understood the people who would telephone the Hotline and say, 'I know all the facts, but I just need you to tell me again that I'll be alright.' That night, my mother called. I didn't know which piece of news would upset her more: that I was gay or that I was HIV-positive. I told her both.

"She kept asking me when I was going to come home. I kept telling her the best treatment was available in New York. 'Yeah,' she said, 'but how are we going to get the body back?' That may not have comforted me, but it did slap me out of my 'woe is me' attitude. I told her I'd have my body burned and shipped back to her in an envelope. Later, I mailed her some GMHC literature instead. I needed her to understand what I was going through, but at that time I couldn't be a teacher.

"Living with AIDS means living with uncertainty."

"The 'best treatment' turned out to be the only drug available then: high-dose AZT. I had so many side effects I couldn't tell what was the drug and what was disease: insomnia, diarrhea, infections in my mouth, night sweats, constant fevers, skin rashes. I lost 70 pounds in 60 days. I told everyone I was on a diet. My suit and tie hid a lot of that weight loss, and I managed to stay awake in most meetings. But after I'd used my vacation and sick time and comp time, my boss started asking for explanations. I was terrified that the truth would cost me my job.

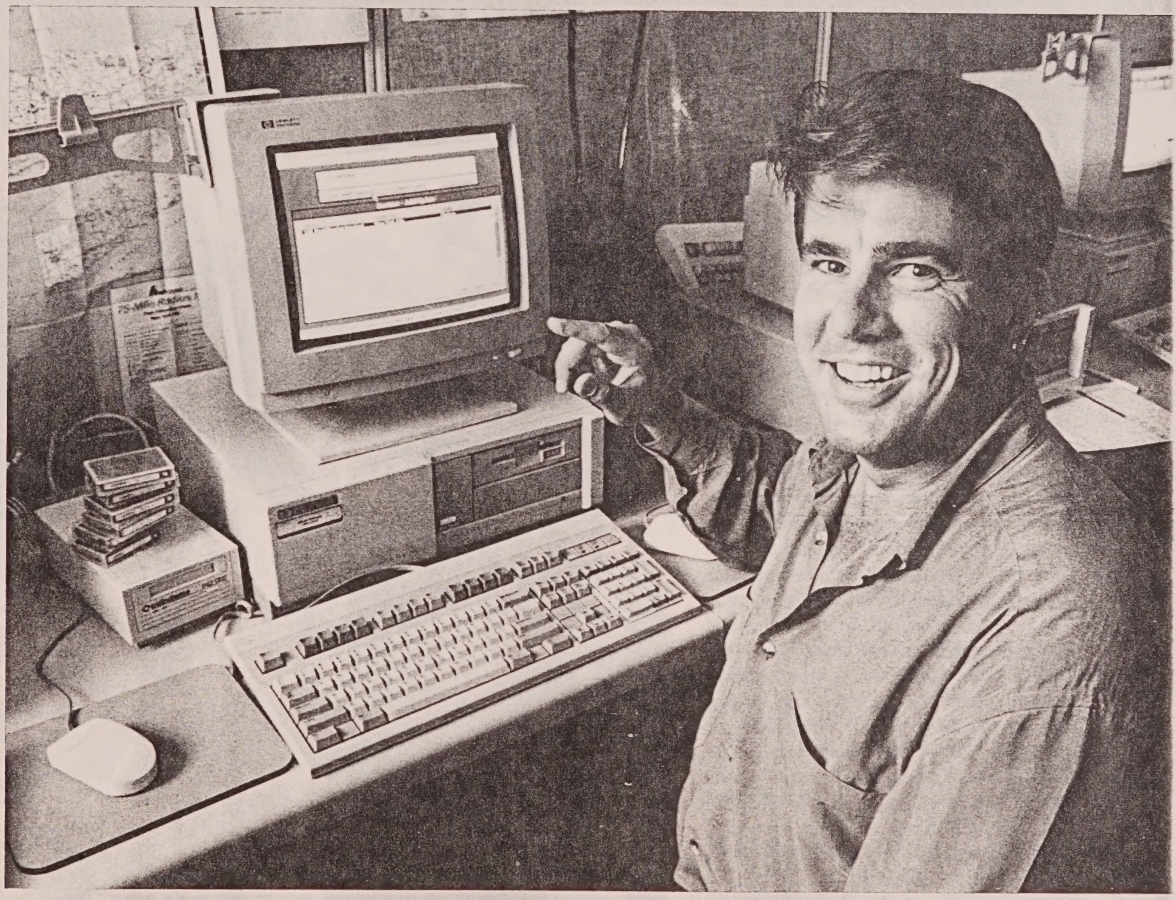
"Once again, GMHC was there to help me work it through. I told my boss, and together we got a GMHC representative to talk to us about how to deal with HIV and other chronic illnesses. This firm was the last place I would have expected to get support, but the plan my boss and I came up with was a dream. For the first time since the holiday party, all the employees in the firm were called together. Company policy, my boss explained during his presentation, was to let all employees with chronic or other health problems work for as long as they felt able. 'Randy has AIDS,' he said, 'and he is still an employee in good standing.' I can still see him sliding a list of hotline numbers and other resources down the conference table and telling everyone to call if they had any questions. It was tense and deadly silent for a few moments. Then my secretary leaned over and said, 'Does this mean we have to be nice to you now?' The ice was broken.

"That support was part of what turned my attitude around. Later, when I did go on disability and leave my job, I volunteered to be a GMHC crisis management partner, and that helped, too. I was hoping my first client would be an easy one, someone like me. He turned out to be a recovering addict with no insurance who'd been evicted while in the hospital. He'd been discharged to an SRO hotel, but no one was sure which. It took me a week to find him.

"Convincing my first client he was worth something, I taught myself that *I* was: that it was okay to admit that you needed support and someone to care for you. Today, I have lots of support. I don't need a buddy now, but if and when I do, I'll be able to ask for one.

"I used to think of the Hotline computerization project as my legacy, the thing I'd leave behind me that would do people good. Since I've been on the Board, there are less tangible things that make me just as proud. I sat in my first Board meetings saying we need more people with AIDS here, more discussion of housing and chemical dependence — not just in our plans, but right here on the Board. Today, that's happened. I used to talk about the need for trainings in multiculturalism, for special support groups for staff members who

have HIV-related illness or who have HIV but no symptoms, and today that's happening. I'll never know what it's like to be black, or a woman. But I do know — as the only gay child of five, as someone who never went to college, as a person with AIDS — I do understand what it's like to have other people point out a difference and use that to ridicule and oppress you. 'You're a fag and deserve to die,' one of my brothers said when I told him I had AIDS. I know how that kind of discrimination can take away your voice.



"I've found my voice at GMHC. There are a lot of us here, volunteers and staff with HIV, who are finding our voices. And when you speak out, you can get so much back. I spoke at the first GMHC Dance-A-Thon and asked the crowd not to be afraid to hug and touch people with HIV, or if necessary, to take care of us. All night long, one after the other, people kept coming over to hug me. People thought I was about to break into tears, but I just wanted to burst out with joy.

"I've had people say, 'You like working with GMHC because you can stop whenever you want to, and don't have to depend on it for a salary.' I don't know what that means. GMHC is my livelihood. I know it can't cure me. But, as the palm reader might say, it's a very, very strong lifeline."

JOAN TISCH, *Donor, Board Member and Volunteer*

"I DIDN'T EVEN KNOW IT WAS AN

epidemic. But very early, several people in my immediate world became sick and died. What could I do about AIDS? I didn't have any nursing experience or social work degrees. I told a friend at a family therapy institute that I wanted to give some time, and she said, 'Wonderful. We're starting a therapy group for families where a member has AIDS. Why don't you go to GMHC and train as a volunteer for a few months, and then come work with us?' I didn't really know what GMHC was. In those days nobody ever even said the name right, or at least nobody in my zip code. People kept calling it 'GMAC' — like General Motors Acceptance Corporation.

"Forty-eight hours later the phone rang and it was the GMHC Volunteer Office. They told me, 'No matter what you can you do, we need you,' so down I went. They tried to teach me how to operate the main switchboard, but that didn't work. I could answer the phone at the Volunteer Office, though, and do paperwork and errands like going to hospitals to straighten out bills.

"A few months later, my friend called from the therapy institute. 'We're ready for you now,' she said. 'I'm not going,' I told her. 'I like it here.'

"We were at 18th Street then, which had tiny little offices and a motorized chair to carry clients who were too weak to walk up the stairs. Sometimes people seemed so fragile it was scary: you'd find yourself staring without knowing that you were staring. Once I was the witness for a will. It was terrible, a young man in his early twenties, younger than my children, having to make a will. Most of the time I did much more basic work, like alphabetizing for hours. But I loved the camaraderie.

"Fundraising was the farthest thing from my mind at that point. I wanted an amount of anonymity. Not that anybody in the Volunteer Office knew who I was. The head of the office, Kevin — he's no longer alive — wanted to walk in the first AIDS Walk, but he had a wooden leg and told me nobody thought he could walk a block. I think he was shocked when I gave him a check for a hundred dollars. 'If this check bounces, I am going to be very embarrassed,' he said to me. I said, 'So will I.'

"Another volunteer, Jerry — he's also died since — was talking to me about work on the Hotline. Then he said, 'I have a very nervy question. I hear your husband's just been made Postmaster General. Do you think we could get a table at the post office?' I think Bob had only been Postmaster General, what, a day and a half? But there is *still* a table with GMHC literature

on it at the FDR Post Office on Third Avenue.

"Then came the call from Nathan Kolodner. Nathan was GMHC's Board President, but I knew him as the director of the André Emmerich Gallery. So when he called, I thought, 'Oh, he has another treasure I can't live without.' But Nathan had sold me all the previous treasures without asking me to meet him at the Four Seasons for lunch. It turned out he'd gone to GMHC to run a Board meeting, picked up the clipboard all the volunteers signed in on, and had seen my name. 'I'm not going to insult your intelligence,' he said. 'My reasons for wanting to see you on the Board should be obvious.' He never asked me to give money directly. I was going to be the credibility bridge between the downtown gay community and the uptown business community.

"I knew Bob and I had the ability to give. And in the year and a half that I'd been at GMHC, I could see that cases were growing tremendously. Clearly it was going to be a private sector problem: the Reagan Administration wasn't doing anything — or at least anything of substance. GMHC was bursting out of the building: files on the floor, the switchboard always jammed up with calls, staff on top of each other. No one complained. But when they decided to move to 20th Street, we helped with a major donation to the Building Fund.

"In the business community, no one could quite figure me out. 'Why this?' people would ask. 'It's a big city. Isn't there anywhere else you could go to volunteer?' My favorite was when a friend of mine — a very bright woman who is still a good friend — asked, 'When you stay down there five or six hours, what do you do when you have to go to the bathroom?' I said, 'The same thing you would do if you had to go to the bathroom.' '*There?* You use *that* bathroom?' This is a very bright woman, but there were a lot of bright people who didn't know how AIDS was transmitted then. I think even my kids weren't sure — they thought it was great that I was working at GMHC, but at what price? Today all three of them are doing AIDS work, two of them with GMHC.

"I have two sets of friends: the friends I see until six o'clock, when my husband comes home, and the ones I see when Bob and I get dressed and go to dinners or the theater or benefits or whatever. The second set has taken longer to reach, but in the overall I think my efforts to get the people I know to show support for this fight have worked quite well. Now, when the subject of AIDS comes up, people say, 'Talk to Joan.' Of course there are still people, even among the supposedly free-thinking, intelligent people we know, who are holdouts — I think because of homophobia. But at least people no longer seem to think that AIDS is always somewhere else. 'What do you mean he died of AIDS? Wasn't he Jewish?' some friends used to say, as if the two things couldn't go together. Or people say, 'I just can't understand it. How does a woman who's not a drug user get AIDS?' 'Think about it a while,' I tell them, 'and if you can't figure it, out we'll talk later.'

"I've spoken to people in the beauty parlor, even at the dinner table, but I hate asking for money. I don't sit down and say, 'Well, now that I'm seated next to you, how about contributing...' I don't think it's appropriate. But I also don't feel it's appropriate for anyone, in a crisis like this one, to stop giving or working. If people don't feel comfortable giving for a gay cause, I'll ask if they know about the services we provide to women, children and families. I believe in what GMHC does that much. And I'm that angry.

"There was an obituary for an entertainment lawyer in the paper recently, a big paid ad that jumped out at me. And the first sentence was, 'Died of AIDS and neglect from the Reagan-Bush Administration.' Now that's very powerful. I agree with that. And until there's a cure, until we stop hearing projections that put out every little ray of hope, I'm going to keep going with GMHC, with what I agree with and what I believe. It's a simple idea, one I grew up with. You give what you can afford."

"Now, when the subject of AIDS comes up, people say, 'Talk to Joan.'"

TONYA HALL, *Client*

"WHEN I WAS DIAGNOSED HIV-

positive in 1985, the doctor gave me one sentence of advice: 'Don't worry, you have two good years left.' I'd never heard of infectious disease clinics, or monitoring your immune system. I wasn't even sure if there were any other women with the virus. For all I knew, I was the only one.

"Three years later, I got double kidney infections and a mouth inflammation so bad I couldn't swallow. The doctors urged me to apply for Social Security, but when I did the government sent me back a letter that said I wasn't sick enough. I went downtown for a 'fair hearing.' It was a madhouse down there, a hundred of us waiting in this filthy room at nine in the morning — families and sick people and people nodding out on benches. When my turn did come, the investigators were sitting right across from me, but they seemed miles away. They kept firing questions: 'Could you cook for yourself?', 'Can you clean for yourself?' Six months later, they sent me some brochures showing smiling people in wheelchairs, and a letter saying that though I couldn't do heavy lifting, I could still find a job.

"A few months after that I had two strokes, and it was the same story. This time they told me that if I had pneumonia or another AIDS-related infection, I could get benefits. I had a seizure instead, and collapsed on a steam pipe that burned all the skin off my lower body.

"I came to six weeks later, wrapped in bandages from my waist to my toes. It took me seven months to recover, lying in a paper robe, on paper sheets, with nurses who were afraid to touch or feed me. Sometimes I'd wake up and find bright orange signs posted over my bed: 'Warning. Contact Isolation.' Some nurses would leave the food tray where I couldn't reach it. 'They don't pay me that much,' one told me. I came to once and found my mother standing over me, hysterical. 'I knew it, I knew it,' she kept saying, 'I knew you'd get AIDS from hanging around those homosexuals.' The rails are up, I'm strapped down in four-point restraints because of the seizures, and I can't reach the call button to get her out of there. It turns out a doctor told her I had the virus while I was in the coma. 'Oh, you mean you didn't know,' he said when he saw the shock on her face. 'I'll send someone in to talk to you.' No one ever came.

"That hospitalization was the first time I knew other women who talked about having AIDS. One girl, Jackie, kept screaming, 'I can't breathe!' every time they shut off the lights. I went over and took her hand and asked her what she was so afraid of. She had dropped from 160 to 83 pounds, had no hair and that eczema you sometimes get from the virus.

"She'd been denied benefits seven times. One day, the social worker came in beaming. 'Jackie will be so happy,' she told me. 'She's been approved!' Jackie had been dead for two weeks.

"I started drinking. I would sneak out in my smiley slippers and Department of Health robe, clutching my catheter and my urine bag like a purse. It was crazy, but I could fit a whole six-pack of tall boys in my diaper. No one ever said anything but the man at the liquor store.

"The hospital did tell me of plans for Project Samaritan, a place especially for people who were both living in recovery and with the virus. When I got out of the hospital, it still wasn't open. I went on a seven month rampage, drinking and doing cocaine. My immune system couldn't handle it — my T-cells dropped to 31. I had thrush all the way down my esophagus, and couldn't even hold down water. I landed in another hospital with alcoholic hepatitis.

"This time the doctors told me, 'Tonya, you're killing yourself. You can't ever drink again.' I looked at them like they were crazy. There was the chief of infectious diseases, his assistant, a group of medical students, the doctor who dealt with liver problems, all standing by my bed. They didn't say, 'You're dying of AIDS.' They said, 'You're killing yourself.' It started hitting me. Drinking and drugs were killing me; AIDS wasn't.

"I got out of the hospital on my birthday, not wanting to go back to the life I'd had. I asked again about Project Samaritan. Now it was open, but there were no beds available. I

"I live AIDS like a challenge, but I look at it like a war."

stayed sober for six months, until the Desert Storm Parade. Then I went crazy again. I took all my AZT to overdose. All I got was gas pains.

"After a detox program I went into Project Samaritan, and someone there recommended GMHC. I'd thought GMHC was like Jack LaLane for gay men — some kind of spa. But when I went for my intake interview, I got into a conversation with another guy about the virus. People were willing to talk so freely. To see people joking and holding their head up — it gave me a sense of hope.

"My financial advocate at GMHC got me a grant for a winter coat and some underwear. I didn't understand anything about the Division of AIDS Services, or food stamps, or my M11Q form to prove my diagnosis, and she helped me with all that. And I don't know what GMHC did, but somebody at Social Security found my application and things started to move again. Today, I get $332 a month to pay my bills and transportation and living expenses.

"It's strange. I'm proud — both to be living with AIDS, and to be clean and sober. But it's easier to talk about having HIV than it is to talk about recovery. Because even in the AIDS community, people don't have the same compassion for drug users and alcoholics. We don't even talk about the effects of alcohol or cocaine on the immune system. Most AIDS doctors don't usually ask you, 'Do you drink or smoke?' They put those habits in the 'comfort category' — like maybe you eat a quart of ice cream a day, but who cares. I used to think, 'I'm taking my medicine. So what if I wash it down with vodka?' I'm working with someone at GMHC now to start a support group for women in recovery, because there are definitely things we need to talk about.

"My family and I are talking, too. My brothers used to joke about girls as notches on their belt — locker room talk. Today, they tell me they're using condoms. My mother asks me questions now: 'What does this mean? What's PCP?' When I tell her my doctor wants to check me for neuropathy, she asks, 'What is that?' Like a lot of women with HIV, I have cervical cancer now, and I think that's easier for her to accept than AIDS. It is something quiet, a woman's burden.

"I live AIDS like a challenge, but I look at it like a war. There have been some long wars. And where is that doctor who told me I had two good years left? I want to tell him something: Don't even think about it! I'm still here."

Letter from the Treasurer

Gay Men's Health Crisis (GMHC) continued its phenomenal growth in the fiscal year ended June 30, 1992 (FY 1992).

Total expenditures during FY 1992 for all of GMHC's programs, services and administration exceeded $21 million, approximately $3 million or 17% more than FY 1991. This number includes the value of donated services, which, based on New York guidelines for not-for-profit organizations, represent close to $2.5 million. However, this valuation of volunteer efforts solely for accounting purposes cannot truly begin to quantify the enormous value of and need for GMHC's volunteer services. Legal and Ombudsman's programs increased $1.4 million, or 19%, over FY 1991. Education program expenditures increased $500,000, or 13%, over FY 1991. GMHC's advocacy efforts continued to grow in light of government's continued reluctance to fulfill its obligations, increasing by $135,000, or 6%, over 1991.

While program spending increase by 15% over the prior year, expenditures for management and fundraising increased by less than $1 million over FY 1991. This is an astonishing result given the increased cost of fundraising due to the recession and reductions in the rate of government funding.

Government grants continued to be a diminishing source of funds. While only reduced approximately $143,000 from last year, this minimal reduction in actual support translates to 15% of total revenue, compared to 17% last year and represents 15 individual government grants versus seven in FY 1991. Accordingly, GMHC must continue to rely on the private sector for the vast majority of its support. Fortunately, the generosity of individuals through direct support, special events (AIDS Walk New York, Circus For Life and the Dance-A-Thon), as well as contributions from corporations and foundations, provided GMHC with over $14.3 million in FY 1992, almost 13% more than last year.

GMHC's Board approved the FY 1992 budget, anticipating that cash receipts would equal cash expenditures (exclusive of depreciation and amortization charges). On a book basis, however, FY 1992 resulted in a deficit of approximately $835,000, due to the inclusion of the non-cash depreciation and amortization charges of approximately $870,000.

GMHC ended FY 1992 financially sound and with unrestricted fund balances (exclusive of property, plant and equipment fund balance) of almost $3.1 million at the end of FY 1991. This amount, however, represents barely two months of GMHC's budgeted operating expenditures for FY 1993. Accordingly, with the continued generosity of its donors and the untiring efforts of its volunteers and staff, GMHC will continue its fight against the HIV epidemic.

Louis A. Bradbury, *Treasurer*

KPMG Peat Marwick

Certified Public Accountants

345 Park Avenue
New York, NY 10154

Independent Auditors' Report

The Board of Directors
Gay Men's Health Crisis, Inc.:

We have audited the accompanying balance sheet of Gay Men's Health Crisis, Inc. (GMHC) as of June 30, 1992, and the related statements of revenue, expenses and changes in fund balances and of functional expenses for the year then ended. These financial statements are the responsibility of GMHC's management. Our responsibility is to express an opinion on these financial statements based on our audit.

We conducted our audit in accordance with generally accepted auditing standards. Those standards require that we plan and perfonm the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of GMHC as of June 30, 1992, and the results of its operations and the changes in its fund balances for the year then ended in conformity with generally accepted accounting principles.

KPMG Peat Marwick

September 18, 1992

Member Firm of
Klynveld Peat Marwick Goerdeler

Balance Sheet

June 30, 1992 (with comparative figures for 1991)

	1992	1991
Assets		
Cash, primarily interest bearing	$ 877,951	2,302,376
Investments (note 3)	2,534,937	1,504,145
Government and other grants receivable	590,841	521,885
Pledges and other receivables (net of allowance for doubtful accounts of $50,000 in 1992 and 1991)	797,343	278,675
Other assets	271,097	152,951
Fixed assets, net (note 4)	10,709,268	10,466,281
Total assets	$ 15,781,437	15,226,313
Liabilities and Fund Balances		
Accounts payable and accrued expenses	$ 580,853	319,448
Deferred public support	1,211,183	262,299
Obligation under capital lease (note 5)	179,476	
Total liabilities	1,971,512	581,747
Fund balances:		
Unrestricted	3,117,897	4,067,556
Restricted	128,236	76,729
Net investment in fixed assets	10,529,792	10,466,281
Endowment fund	34,000	34,000
Total fund balances	13,809,925	14,644,566
Total liabilities and fund balances	$ 15,781,437	15,226,313

See accompanying notes to financial statements.

Statement of Revenue, Expenses and Changes in Fund Balances

Year ended June 30, 1992 (with comparative totals for 1991)

	1992					
	Current funds					
	Unrestricted	Restricted	Plant fund	Endowment fund	Total	1991 Total
Revenue:						
Public support:						
Contributions	$ 6,095,282	577,125	27,538		6,699,945	5,176,244
Donated services (note 7)	2,500,363				2,500,363	2,489,338
Established memorial funds	162,687				162,687	156,824
Special events (net of direct benefit costs of $258,120 and $211,674 in 1992 and 1991, respectively)	7,394,837				7,394,837	7,295,466
Government grants		3,039,223			3,039,223	3,181,844
Total public support	16,153,169	3,616,348	27,538		19,797,055	18,299,716
Other revenue:						
Investment income	98,125				98,125	207,567
Rental income (note 4)	155,595				155,595	119,250
Publication sales	201,840				201,840	143,251
Total other revenue	455,560				455,560	470,068
Total revenue	16,608,729	3,616,348	27,538		20,252,615	18,769,784
Expenses:						
Program services:						
Client programs	5,944,972	2,304,002	448,712		8,697,686	7,336,916
Education	3,248,903	1,059,795	233,985		4,542,683	4,026,709
Public policy development, information and advocacy	2,161,253	50,797	77,983		2,290,033	2,155,030
Total program services	11,355,128	3,414,594	760,680		15,530,402	13,518,655
Supporting services:						
Management and general	1,035,161	88,825	59,962		1,183,948	1,065,862
Fundraising	4,312,432	11,803	48,671		4,372,906	3,491,873
Total supporting services	5,347,593	100,628	108,633		5,556,854	4,557,735
Total expenses	16,702,721	3,515,222	869,313		21,087,256	18,076,390
Excess (deficiency) of public support and other revenue over expenses	(93,992)	101,126	(841,775)		(834,641)	693,394
Other changes in fund balances:						
Plant acquisitions and debt service from current funds	(855,667)	(49,619)	905,286			
Fund balances at beginning of year	4,067,556	76,729	10,466,281	34,000	14,644,566	13,951,172
Fund balances at end of year	$ 3,117,897	128,236	10,529,792	34,000	13,809,925	14,644,566

See accompanying notes to financial statements.

Statement of Functional Expenses

Year ended June 30, 1992 (with comparative totals for 1991)

	1992						
	PROGRAM SERVICES			SUPPORTING SERVICES			
	Client Programs	Education	Public policy development, information and advocacy	Management and general	Fundraising	Total	1991 Total
Staff compensation	$ 3,383,680	1,603,493	692,970	532,420	457,860	6,670,423	5,267,430
Employee benefits and payroll taxes	883,730	406,963	153,321	115,592	105,033	1,664,639	1,205,829
Donated services (note 7)	2,057,381	442,982				2,500,363	2,489,338
Professional fees and contract service payments	273,234	373,752	219,056	152,419	1,361,606	2,380,067	2,163,195
Postage and shipping	47,506	91,667	90,594	6,457	711,786	948,010	606,811
Telephone	160,129	80,475	28,055	20,241	79,668	368,568	237,007
Occupancy	274,847	143,296	52,961	36,879	34,154	542,137	523,873
Supplies	122,544	56,268	18,939	20,162	59,587	277,500	300,134
Printing	90,728	330,684	141,320	487	970,318	1,533,537	1,337,654
Equipment rental and maintenance	84,671	42,841	11,782	12,083	17,579	168,956	126,224
Memberships and subscriptions	10,721	10,138	5,950	3,610	3,191	33,610	35,438
Staff and volunteer training and support	79,073	42,090	9,749	21,780	11,227	163,919	179,448
Meetings, travel and related costs	100,841	85,524	40,826	44,643	70,924	342,758	468,016
Marketing and promotion	30,419	116,415	352,506	13,367	306,619	819,326	711,084
Staff recruitment	23,014	30,463	12,714	11,146	34,281	111,618	122,772
Other program expenses	89,771	352,329	25,154			467,254	342,762
Nutrition program	172,123					172,123	113,922
Grants to other AIDS service organizations	131,561	73,462	225,505			430,528	598,500
Direct financial aid	145,889					145,889	131,402
Insurance	17,791	5,506	1,426	51,667	8,981	85,371	110,407
Taxes and interest	6,852	4,673	4,697	35,412	784	52,418	18,963
Direct lobbying expenses			118,065			118,065	133,046
Other special event costs	26,046	5,333			69,860	101,239	59,263
Miscellaneous	36,423	10,344	6,460	45,621	20,777	119,625	139,202
Total expenses before depreciation and amortization	8,248,974	4,308,698	2,212,050	1,123,986	4,324,235	20,217,943	17,421,720
Depreciation and amortization	448,712	233,985	77,983	59,962	48,671	869,313	654,670
Total Expenses	$ 8,697,686	4,542,683	2,290,033	1,183,948	4,372,906	21,087,256	18,076,390

See accompanying notes to financial statements.

Notes to Financial Statements

1 Organization

Gay Men's Health Crisis, Inc. (GMHC) was incorporated under New York State law on June 25, 1982. GMHC, the world's first AIDS organization, founded by members of the gay community, committed to the practice and realization of multiculturalism, and whose services are provided principally by volunteers, has as its purposes: maintaining and improving the quality of life for persons with AIDS (PWAs), symptomatic HIV infection and their carepartners; advocacy for fair and effective public policies and practices concerning HIV infection; and through education and AIDS prevention programs, increasing awareness and understanding of HIV infection.

GMHC volunteers, under the supervision of professional staff members, deliver a variety of direct services, education and advocacy for people with HIV infection, their carepartners and loved ones.

■ **Client Programs.** In Client Services, Intake Clinicians conduct intake interviews to assess new clients' needs and help them choose which GMHC services best meet those needs. Volunteers assigned as buddies help with chores clients can no longer handle themselves. Crisis Intervention Workers (CIWs) are assigned when more intensive emotional support is required. Crisis Management Partners combine functions of both buddies and CIWs for clients needing professional monitoring for physical and emotional needs. Group Leaders facilitate the many support groups GMHC offers clients, their carepartners, loved ones and friends. Financial Advocacy counselors direct clients to the proper government financial aid programs and help them receive benefits to which they are entitled. The Child Life program provides services to families with AIDS by offering babysitting, outings and other support to children affected with HIV disease, their siblings and parents. The Recreation Program offers diverse services, social activities and special events.

The Office of the Ombudsman advocates for PWAs who are not receiving adequate services from health care providers, hospitals and related services.

Through the Legal Services Department, staff and volunteer attorneys provide direct services to GMHC clients, including estate planning, powers of attorney, living wills, as well as legal matters involving insurance, housing, discrimination, immigration and personal finances.

■ **Education.** In the Education Department, staff and volunteers operate the Hotline, handle Speakers Bureau engagements, help conduct public education seminars, advertise and facilitate safer sex workshops, and aid in the production of publications and videos.

The AIDS Professional Education Program trains mental health professionals about the concerns of HIV-infected individuals.

Started last year, GMHC's Technical Assistance Program offered thousands of hours of help to AIDS organizations, universities and other human service agencies with issues such as program development, fundraising, nutritional trainings and computer support. GMHC's Fellowship Program in fiscal 1992 offered month-long training sessions to numerous AIDS professionals from AIDS service organizations around the country.

■ **Public Policy Development, Information and Advocacy.** The Policy Department utilizes a state-wide telephone and mail network to call legislators when HIV-related voting occurs. To push for favorable bills and against unfavorable legislation, full-time lobbyists are employed in Albany and Washington, D.C. In the Communications Department, volunteers and staff write, design, photograph and edit regular publications and special projects. In fiscal 1992, Communications created an advocacy campaign that combines full-page advertisements, paid radio spots and press conferences to heighten public awareness on important policy issues.

2 Summary of Significant Accounting Policies

■ **Fund Accounting.** The accompanying financial statements are presented in accordance with the industry Audit Guide, *Audits of Voluntary Health and Welfare Organizations*, published by the American Institute of Certified Public Accountants.

To ensure observance of limitations and restrictions placed on the use of resources available to GMHC, the accounts are maintained in accordance with the principles of fund accounting. This is the procedure by which resources are classified for accounting and reporting purposes into funds that are unrestricted or restricted. Externally restricted funds may only be utilized in accordance with the purposes established by the source of such funds. Unrestricted funds are funds which have no restrictions imposed by donors, grantors or other outside parties and, accordingly, may be used for any purpose in achieving the organization's goals.

The endowment fund represents resources that are subject to the restrictions of the gift instrument which require, through the year 2000, that the principal be invested and that only the income from investments be used.

■ **Revenue Recognition.** Contributions and pledges are recorded as revenue when pledged or received unless designated by donors for use in future years in which case they are deferred.

Resources from government grants are recorded as support when the related costs are incurred.

■ **Investments.** Investments are presented in the financial statements at cost or at fair market value at the date of the gift, if contributed.

■ **Fixed Assets.** Fixed assets are reflected in the accompanying balance sheet at cost, or at fair market value at the date of the gift, if contributed. Depreciation and amortization have been provided on the straight-line method over the shorter of estimated useful lives of the assets or the life of the related lease, respectively.

■ **Tax-Exempt Status.** GMHC is a New York not-for-profit corporation exempt from Federal income tax under Section 501(c)(3) of the Internal Revenue Code (the Code). Contributions by donors qualify for the maximum charitable contribution deduction. In fiscal year 1991, GMHC elected to operate under Section 501(h) of the Code in order to participate in limited lobbying activities regarding AIDS-related issues without jeopardizing its exemption from income taxes under Section 501(c)(3).

■ **Reclassifications.** Certain reclassifications of prior year's balances have been made to conform to the current year's presentation.

3 Investments

The cost and market value of investments are presented below:

	1992	
	Cost	Market value
Liquidating trust (not readily marketable)	$ 63,891	63,891
Money market accounts	2,471,046	2,471,046
	$ 2,534,937	2,534,937

	1991	
	Cost	Market value
Liquidating trust (not readily marketable)	$ 74,626	74,626
U.S. Treasury bills	836,535	843,336
Money market accounts	592,984	592,984
	$ 1,504,145	1,510,946

4 Fixed Assets

Fixed assets consist of the following:

	1992	1991
Land	$ 731,740	731,740
Building and building improvements	8,395,052	8,327,381
Leasehold improvements	1,199,088	659,664
Furniture and equipment	2,942,840	2,437,635
	13,268,720	12,156,420
Less accumulated depreciation and amortization	2,559,452	1,690,139
Fixed assets, net	$10,709,268	10,466,281

GMHC has leased a portion of its building to an unrelated not-for-profit organization. Such lease arrangement expires on December 31, 1993 and requires annual minimum rental payments as follows:

Year ending June 30,	Amount
1993	$ 129,850
1994	66,250

5 Obligation Under Capital Lease

GMHC is obligated under a capital lease for office furniture expiring January 31, 1997. At June 30, 1992, the asset balance of such leased furniture was $174,127, net of accumulated depreciation of $19,348. The following is a schedule of future annual minimum lease payments under the capital lease together with the present value of the net minimum lease payments as of June 30, 1992:

Year ending June 30,	Amount
1993	$ 44,900
1994	44,900
1995	44,900
1996	44,900
1997	26,191
Total minimum lease payments	205,791
Less: amount representing interest	26,315
Present value of net minimum lease payments	$ 179,476

6 Real Property Lease Commitment

GMHC is obligated under operating leases for office facilities, expiring at various dates through January 31, 1999. Future minimum annual rental payments through 1999 are as follows:

Year ending June 30,	Amount
1993	$ 312,300
1994	214,700
1995	198,000
1996	168,500
1997	52,000
Thereafter	82,300

Rent expense for the year ended June 30, 1992 was $211,027

7 Donated Services

Numerous volunteers have contributed many hours to GMHC to provide services to persons with AIDS, conduct fundraising and provide administrative support to the organization. GMHC has valued the program-related services according to New York State guidelines for grant reporting purposes because those services constitute an integral part of the efforts of the organization and would be purchased if not provided by volunteers. Equivalent amounts of revenue and expense are recognized for these services.

8 Line of Credit

GMHC has a $2,000,000 line of credit available to support seasonal working capital needs. This line of credit will expire on December 31, 1992. On November 8, 1991 and May 14, 1992, GMHC borrowed $1,000,000 and $500,000, respectively, against this line of credit. The loans were repaid in December 1991 and June 1992, respectively, including interest at the then existing prime rate. At June 30, 1992, GMHC had no amounts outstanding on this line of credit. No commitment fee is required for this line of credit.

Supporters of Gay Men's Health Crisis

Gay Men's Health Crisis depends on the passion and generosity of many thousands of volunteers and contributors to fulfill its mission of providing services, education and advocacy for men, women children whose lives are affected by HIV illness.

These services are delivered by our dedicated corps of 2,300 volunteers, whose efforts this year were valued at $2.5 million. The true worth of volunteer commitment, however, is inestimable.

We wish to express our deepest gratitude to all of our supporters. In addition to the gifts listed below, very special thanks to the unlisted individuals, corporations and foundations whose contributions of time and financial support allow us to continue the fight against AIDS.

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Monie Love
Patti lu Pone
Madonna
Ann Magnuson
Lisette Melendez
New York City Gay Men's Chorus
Tonya Pinkins
Tony Randall
Al Roker
Susi Simpson
Toby's Troupe

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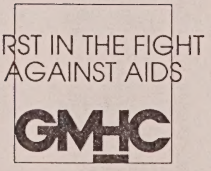

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ALABAMA 35255
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BOB AXELTON
Education Coordinator

JUDY IRVING
Volunteer Coordinator

April, 1992

Dear Friend,

As a client, stipend worker, and volunteer at Birmingham AIDS Outreach, I have had the opportunity to benefit from programs described in the attached Service Report, at the same time, shared in the challenge of seeing that those programs remain available. Under the leadership of Patricia, Susie, and Cindy - the agency's only full time paid staff - BAO struggles to maintain a menu of services to those of us living with HIV, our families and friends, while reaching out to educate the community. As a person living with HIV, I am asking for your continued financial support to BAO.

Daily, I have been impressed by the dedicated volunteers who make possible many of the services BAO offers. Volunteers are the measure of the store of goodwill that BAO stewards Persons Living With HIV / AIDS. From my attendance at BAO sponsored support groups and the special friendship I have with my buddy, I can speak to the importance of those intangible "emotional support" services the agency provides. Volunteers produce our newsletter, fill our speakers bureau, and work on fundraising events. They show generosity of spirit I would not have believed possible before I got involved at BAO. I hope that in at least small ways they find themselves rewarded.

In the wake of Magic Johnson's announcement of his HIV status, I was proud that BAO was able to respond effectively to demands for reliable HIV information. BAO has become the most visible AIDS service

organization in our region. Our helpline is accessed daily by folks in need of information and emotional support. By participating in health fairs we are spreading the word about HIV prevention, testing, and treatment, and demonstrating that we are responsible citizens in the face of this health crisis. Through our speakers bureau, we are putting a face on the epidemic and making it harder for many people to hide behind the excuse that they have never known anyone with AIDS.

The sad reality is that this epidemic is not about to end. BAO will need regular, dependable, and substantial financial support to continue its mission of empowering people who are living with HIV and educating the community. We have been blessed with donors who contribute regularly to our special events, like this June's "An Event in Three Acts." We also have a sustainer program that allows regular giving during the year. You can earmark your donations for specific programs, like direct financial assistance to Persons Living With HIV / AIDS. I won't say that becoming a sustainer is a "painless" way to give but in the course of a year your regular contributions can provide funds BAO can count on, and it can buy you the assurance that BAO will be there when you or someone you love needs help.

Sincerely,

Adrian Daniels

Adrian Daniels

P.S. Please help. Send your donation today.

SERVICE REPORT

1991

MISSION

The mission of Birmingham AIDS Outreach is to improve the quality of life for people affected by HIV through direct services, advocacy, and education.

GOALS

GOAL I: To provide direct services to those affected by HIV.

GOAL II: To serve as an advocate for people affected by HIV.

GOAL III: To reduce the further spread of HIV.

GOAL IV: To develop an adequate and diversified funding base.

GOAL V: To monitor needs and gaps in services during the emerging crisis.

GOAL VI: To develop a responsible and accountable organization.

CLIENT SERVICES

• Birmingham AIDS Outreach provides a wide range of services to people living with HIV/AIDS, their families, friends and partners. Services range from practical support with food, errands and medical bills to emotional support helping clients overcome the challenges of living with HIV/AIDS.

• Demand for Client Services has been doubling every 6 months over the past 2 1/2 years. We expect to see this increase in demand continue into the indefinite future.

• BAO served 138 new clients in 1991. Thirty-four clients have died since May. Over 180 persons who are HIV+ received services from BAO in 1991.

PRACTICAL SUPPORT

• Emergency Financial Assistance provides emergency help with medical bills, rent, and utilities. Disbursements grew by 68% to $44,000 last year.

• The Stipend Program gives BAO clients an opportunity to work in the fight against HIV/AIDS in return for help with direct payment of bills. This program served 34 clients during the past year, increase of 700%.

• The "Clothes Closet" continued to provide clothes, wheelchairs, hospital beds, refrigerators, walkers and bedside commodes to persons living with HIV/AIDS. Two hundred and forty persons used this service last year, a 260% increase.

• The Food Bank continues to provide persons living with HIV/AIDS with canned goods, toiletries, nutritional supplements. BAO has begun helping people living with AIDS to access the Food Share program. The Food Bank was used by 301 persons last year, an increase of 335%.

• Transportation Volunteers took over 150 persons to clinic appointments, pharmacies and doctors' offices last year. Additionally, the Transportation Volunteers began helping clients with moving last year.

• Intake and Referral Assistance was extended to 205 clients last year helping people living with HIV/AIDS to access services provided by outside agencies.

• Holiday Gift Bags were distributed to over 108 clients in 1991 with the generous assistance of the Junior League. The Junior League also hosted our first Holiday Party for persons living with HIV/AIDS. These heartfelt efforts provided many people living with HIV/AIDS with their only holiday celebrations last year.

EMOTIONAL SUPPORT

• The Buddy Program provides one-on-one volunteer emotional support and services for clients and their families by pairing a person living with HIV/AIDS with a trained buddy. Buddies go through an intensive 3-day workshop emphasizing the building of a Buddy Team, grief processes and communication skills. The Buddy Program was serving 24 clients by December.

EMOTIONAL SUPPORT (Continued)

• Support Groups bring together people with AIDS, friends, family members and HIV - positive persons. BAO is currently sponsoring 3 groups, an increase of one group in 1991. Professional counselors came on to facilitate two of these groups in 1991. Total attendance at the 3 groups averages 40 persons per week.

• Positive Attitudes, a group which meets monthly at St. Andrew's Episcopal Church for a buffet dinner, brings in experts to address issues about living with HIV. Approximately 420 persons attended Positive Attitudes in 1991.

EDUCATION PROGRAMS

• The Help Line is staffed by trained volunteers and stipend workers 8 a.m. to 10 p.m. Monday through Friday. Handling approximately 500 calls per month, Helpline volunteers provide callers with information on HIV testing, modes of transmission, referrals to medical or legal services, and resources for food, shelter, clothing and financial help. Following Magic Johnson's announcement, BAO joined with Channel 13 and the Crisis Center at United Way to field over 400 calls per day.

• Women's Risk Reduction Education was offered on numerous occasions throughout the year to help participants determine their need to be tested and to help them develop safer lifestyles.

• Newsletters are the Outreach, which is published bi-monthly, and Center For AIDS Research Questions, a joint venture project of UAB's Center for AIDS Research and BAO, published quarterly, offering up-to-date technical information on drug treatments, treatment procedures and the nature of HIV. Both newsletters are distributed free to a mailing list of almost 10,000 persons by BAO.

• Resource Center provides a clearinghouse and information library at BAO for review and distribution of HIV/AIDS information. The Resource Center brings a local focus and response to national issues on request from local print, radio and television media.

• Bar Outreach provides Safer Sex information at local gay bars. This program provides information exhibits and zaps bars at busy times with "Rubbermen" distributing condoms and safer sex information.

• Condom Distribution through BAO is free, and in combination with other safer sex resources helps encourage safer sex practices.

NETWORKING

• HIV/AIDS Alliance of Alabama succeeds the CBO Advisory Committee and is a coalition of BAO's counterparts statewide, providing technical assistance, funding information and advocating enlightened response to the epidemic by state agencies. The Executive Director of BAO served as Chair in 1991.

• The United Way AIDS Subcommittee assists the United Way in establishing AIDS policies for their agencies. BAO has been represented on this subcommittee since its beginning in 1989.

• BAO Interfaith HIV Advisory Committee is a new effort which encourages local churches to become active in filling AIDS service gaps for persons living with HIV/AIDS.

NETWORKING (Continued)

• Birmingham Response to AIDS is a city wide service providers group which meets monthly to exchange information and discuss current HIV/AIDS issues. The Executive Director of BAO served as Chair in 1991.

• Persons Living With HIV/AIDS Advisory Committee meets with BAO's Executive Director to air concerns of persons living with HIV/AIDS, discuss policy and voice the needs of local people living with AIDS.

A BABY'S PLACE

• A Baby's Place is a foster home located in the Birmingham area. The home provides love, emotional support and human bonding essential to infants and children living with AIDS. During 1991 an independent Board of Directors was formed for A Baby's Place to enable the establishment of new services for children outside the foster home. BAO provides the home for A Baby's Place. The Children's Aid Society licenses the facility and administers funding from the United Way and the Department of Human Resources.

VOLUNTEERS

• With a small staff and a growing client base, BAO relies heavily on volunteers for providing client services, special event and office support, speakers bureau, and publicity.

• All volunteers and directors are required to attend volunteer orientation to learn the basics about HIV/AIDS and BAO. We attempt to place volunteers in an area in which they have a particular interest.

• As the public has become more aware and more educated about HIV/AIDS, we have seen a tremendous increase in the number of persons coming forward and volunteering in an effort to "make a difference." Volunteers are the "heart and soul" of BAO.

• In the last quarter of 1991, we added over 75 volunteers. This was largely due to the success of ONE NIGHT STAND-UP 1991.

FUNDING

• The biggest news of 1991 was a grant of $250,000 to BAO to purchase the Swann Building, an historic 21,000 square foot office building in the Lakeview neighborhood. BAO will administer the Swann Building to provide office and meeting space for all agencies providing services to persons living with HIV/AIDS as space permits. Special thanks to Mayor Arrington. The City of of Birmingham is also BAO's largest single source for operational funding.

• The State of Alabama continued to provide funding.

• The Jefferson County Commission appropriated $20,000 to BAO for educational funding - 1991 92.

• BAO continues to receive substantial support from local charitable institutions and corporations. Individual donations increased by 80% over 1991.

• Direct Giving continues to be very important involving direct payment of client needs by churches and individuals and direct donation of needs such as a hospital bed or other equipment.

FUNDING (Continued)

• BAO worked with Birmingham Repertory Theatre to present Miss Evers Boys raising $19,000 and One Night Stand-Up raising $120,000 including the proceeds generated by the sale of Toni Tully's generous donation of the stage backdrop. Very special thanks as well to BE&K and Ted C. Kennedy, CEO of BE&K.

• In 1991 BAO produced a video describing its programs and mission, its first Annual Report and hosted the first Annual Donor brunch in appreciation of the financial supporters that make our work possible.

BAO ADVISORY COMMITTEE

Nina Botsford
Judy Bridgers
Katherine Cabaniss
Claud Cotten
Roger Dube
Rebecca M. Dunn
Cathy Friedman
Commissioner Jim Gunter
Lee Howell
Gloria Howton
Sylvester Jones
Ann Knight
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Jane Mobley
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Kate Nielson
Martin Platt
Judge Sandra H. Ross
Virginia Russell
Dr. Michael Saag
Fern Singer
Jim Sokol
Peggy Sparks
Frances B. Stitt
Adele A. Stockham
Toni Tully
Mimi W. Tynes
Cameron Vowell
Genie Wehling
Louis Willie

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(Amounts Greater Than $100.00)

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Gold Supporters
$1,500.00+
Alabama Power Company
First Nat'l Bank of Jasper
South Central Bell
Vulcan Materials

Silver Supporters
$1,000.00+
AMI Brookwood
AmSouth Bank
Anesthesia Services
Birmingham Health Care For The Homeless
Brasfield & Gorrie
Bruno's
Cooper Mitch
Eastern Health Systems
Ebsco
Ernst & Young
Health South Rehabilitation
Parisian
Protective Life
Saint Lukes Episcopal Church
Saint Vincent's Hospital
SouthTrust Emply. Charity
Southern Company Services
Summitt Medical Center
Supreme Beverage
UAB
UAB Health Services Found.

Bronze Supporters
$500.00+
Baxley, Dillard & Dauphin
Birmingham News
Brookwood Hospital
Bottega, Inc.
Cherokee Bend South Garden Club
Fraternal Order of Eagles
McNolia's
Ronne & Donald Hess Charity Found.
Southern Secretaries
Thompson Tractor
Today American Management

$250.00+
Alabama Theatre
Alabama Car Rental
Birmingham News Employee Fund
Bradley Arant
CMCC
DIFFA
Fastix
KPMG Peat Marwick
Mystick Krewe of Apollo
Mayer Electric
Rainbow Electric
Sloss Development Group
SouthTrust Bank
Southern Ready Mix
UAB Hospice
UAB Medical & Educ. Found.

$100.00+
AKA Sorority
Birmingham Budweiser
Birmingham Centennial Sertoma Club
Birmingham Coca Cola
Birmingham Community Church
Budget Cleaners
Eunice Crabtree
Fairfield Emblem Club
Futon Furnishings
Hewitt Trussville Junior High School
IBM
Lodestar Books
Nat'l Bank of Commerce
Paperr Works
Smith & Hardwick
Southside Properties
Steiner Bressler Advertising
Suburban Ambulance
UAB Head Nurses
Vulcan Chemical
Vulcan Amusement

PRIVATE SUPPORT, INDIVIDUAL DONORS

Platinum Donors
$1,000.00+
Pat Cather
John Falkenberry
Charles Foshee
John Fuller
Dale Gann
Jean Jacque & Rachel Gaudel
Jessica Germany
Jannette Howell
Lee Howell
Judy Irving
Martha Isom
Milton & Joan Jacobson
Rt. Rev Robert O. & Peggy Miller
Gary Northrup
Cindy Owen
Greg Pence
Nan Pizitz
Bob & Peggy Roberts
Mike Saag
Rena Hill Selfe
Dorothy Shaw
Scott & Cameron Vowell
Phillip & Cherie Woods
Alan Zeigler

Gold Donors
$500.00+
Roswell Ashford
Jeanne Cabral
Mike Callahan
Claud Cotten
Janet Cox
T. W. DeCair
Ron & Eleanor Delbene
Joel Dillard
David Flowers
Sam Franks
Paul & Cathy Friedman
Jim Gray
Mike Harris
Gary Hill
Earline Howell
Dan Johnson
Ron Johnson
Martha Jordan
Doug Langley
Kathy Livingston
Dennis Luft
Jack McCullough
Roger McCullough
Max Michael
Joni Pepper
Terry Proctor
Stuart Rachels
Pat Smith
Alan Tichansky
Susan Vaughn
Lee & Yvonne Walls
Katherine Weed
Bill Whisenant
Phillip Williams
W. Carvell Woodall

Silver Donors
$250.00+
Evelyn Allen
Rolla Beck
Chris & Mary Boehm
Phillip Boggs

1991 REVENUE SOURCES
(Amounts Greater Than $100.00)

$250.00+ (Cont.)
Dan Boyd
Garry Brown
Mike Calvert
Chris Carter
Anne Chace
Dana & Mike Chang
Jerry & Sherry Cherner
Charles Collins
Glenn Conn
Billy Cox
Sallie Creel
Adrian Daniels
Ben Davis
Dianne Diamond
Susan Durham
Glenda Elliott
Jim Embleton
Marvin & Ruth Engel
Rita Gibbon
Richard Goldstein
Bo & Kaye Grisham
Juan Fra Guticree
Cynthia Haddock
Felix Harris
Robert Haughton
Phil Heartbug
Pam Hebert
Jim Hooker
Eric Hunter
Mary Kessler
Katheryn Knowlton
Margaret Ann Mayfield
Cheryl McDonald
Gordon Miles
Katheryn Blount Miles
Rabbi Jonathan & Judy Miller
Jane Mobley
Michael Moody
Barry Norris
Katheryn Perley
Michael Pizitz
Henry Ray
Skip Reach
Scott & Susan Robertson
Joel & Bunny Rotenstreich
Perrry Schwartz
Barbarra Seiler
Thomas Spina
Mary Standen
John Stewart
Wes Tallon
Patricia Todd
David Toomey
Richard Tubb
Jerry & Sherry Turner
Richard Wells
Maralyn Williams
Wil Williams
Michael Wilson
Lewis Windham
Michael Wooley
Mark Hickson, III

Bronze Donors
$150.00+
J. Thomas Barnett
George Beals
Brian Beavers
James Blackshear
Sheila Blair
Maralyn Briles
Bob Burns
Linda Curleen
David Clements
Vickie Clemmer
Phillis Coggans
Jim Cone
Gilbert Cormillon
John Elder
H. W. & Frances Farris
Cherie Feenker
Eddie Friend
Robert Glaze
Joy Godsey
Dan Halcomb
Doug Hale
James Harbour
Robert Henger
Michael Hewett
Leslie Hicks
William & Gloria Howton
Frank Hrabe
Craig & Patrick Jones
Cary & Catherine Ketchum
Barbara Hall Key
Deanna Lucas
Lucy Morron
Bill Mudd
Michelle Parr
Amanda Robinson
Jim Rye
George Shaw
Fern Singer
David Sperling
Gayle Stephens
Mary Stewart
Nonie & Bill Swader
Ben Swiley
Robin Taylor
William Thacker
Jeff Thomas
Cameron Tichenor
Tasha Tillman
Virginia Volker
Janice Ware
Howard Wilkins
Deb Watring
John & Elaine Whitaker
John Wiley

$100.00+
Livy Beck Abele
Michael & Amy Allen
Elizabeth Archibald
Greg Attaway
Joseph Barra
Deborah Baugh
Sue Bell
Ray Benson
Eugene & Jan Bergose
Bill & Judy Bridgers
Sybil Burton
Steve & Chuck Carter
William Carter
Lydia Cheney
Lynn Clark
Forrest Cook
Jospeh Daniel
Judith Doogan
Andy Downs
Russell Drummond
Marc & Martha Eason
Molly Engle
Lisa Engle
Pepper Ezelle
Robert Farley, IV
Jane French
Steve Gilmer
Virginia Gilmer
Allan Goldstein
Harvey Gottlieb
Joyce Greathouse
Janet Gresham
Margaret Grubb
Steve Haeberle
Sarah Hays
Donald Hicks
Janice Hyde
Mark Jemison
Bill Jenkins
Thomas Jung
Hurley Knott
Carol Lesniak
Lisa Malone
Garrison Meighan
Louis & Kathy Mezrano
Ann Mullengardon
Katherine Nelson
Bob Penney
Jimmy Nicholson
Paula Pointer
F. H. Powers
Robert Raiford
Debbie Ramseur
Harold & Grace Roberts
Edward Robbins
Harold Rohdy
Lewis Rylee
Dennis Sanchez
Patty Sears
James Simmons
James Earl Smith
Tom Struzick
Donna Tumsula
Toni Tully
William Tynes
Lillian Vann
William Veach
Neal & David Warren
Doyle Waters
Mary Whall
Donald Wilson
Amanda Wilson

1991 In Kind Contributors ($100 or more)

PRIVATE BUSINESS SUPPORT

Alabama Art Supply
Alabama's 13 - WVTM
AmSouth Bank
Ann's Balloons
Baptist Church of the Convenant
BE&K, Inc.
Birmingham Coca Cola Bottling Company
Birmingham Frame & Art
Bottega
Boutwell Recording Studio
Burger Phillips Centre
Cathedral of the Advent (AIDS Outreach Commission)
City Stages
Color Unlimited
Comedy Club
Covenant Metropolitan Community Church
D.J.'s Greenhouse
Doodles
GSC Sound & Light
Highland Bar & Grill
Independence Travel
Joseph McClure Real Estate
Kathy G's Catering
Kay Stroud Photography
Kopping Out Printing
Lee Isaccs Photography
Lewis Advertising
Litho Plate & Negative
Looking For A City Diner
Magic Muffins
McNolia's
Mystic Krewe of Apollo
O'Carrs Deli
Park Lane Flowers
Pickwick Hotel
Pickwick Conference Hotel
Richard Tubb Interiors
Sloss Development Group
Smith & Hardwick Store
South Central Bell / ICAC
Space One Eleven
St. Luke's Episcopal Church
St. Andrew's Episcopal Church
Supreme Beverage Company
Supreme Beverage
The Rage
Tracy's
Tutwiler Hotel
Unity Church
WERC
WMJJ - Magic 96

INDIVIDUAL IN-KIND SUPPORT

Martha Andrews
Anne Arrasmith
Ron & Judy Barron
Honey Bigelow
Gilbert Cormillon
Adrian Daniels
Ron Delbene
Mary Duke
John Falkenberry
Mimi Ferry
Frank Flemming
Sally Harper
Jim Hooker
Stephen Ioy
Thomas Baddiley, Jr.
M. F. Knight
Maureen McGovern
Rick Melton
Mark Middlebrooks
Charlie Muse
Patty Pizitz
Georgann Saunders
Christopher Sibling
Chuck Steward
Peggy Tipton
Frank Trechsel
Toni Tully
Linda Verin
Lester Wallace
Lee & Yvonne Walls
Danny Weaver
Gary Weinberger
Jennifer Willard
Michael Woolley

Birmingham AIDS Outreach

Proposed Budget
1992

REVENUES	1992
General Donations	$ 20,000
Individuals	2,000
Churches	5,000
Corporations	5,000
Sustainers	
BAO Special Events	
One Night Stand-Up	
Spring Event	
Event in Three Acts	170,000
Walk For Life	20,000
Other	5,000
Non-BAO Event	10,000
Celebrate	15,000
Grants	
Chicago Resource Center	10,000
Other	10,000
Governmental Agencies	
City of Birmingham	71,250
Jefferson County	20,000
State of Alabama	23,000
UAB Benevolent Fund	9,825
Contracts	2,000
Products	2,250
Bank Interest	500
Other Revenue	1,000
Asset Transfer	0
Total	$402,075

EXPENSES	
Salaries	
Executive Director	$ 31,500
Director of Programs	25,000
Office Manager	17,000
Bookkeeper	8,000
Volunteer Coordinator	9,000
Benefits	
Executive Director	4,200
Director of Programs	3,000
Office Manager	2,500
Bookkeeper	
Volunteer Coordinator	

EXPENSES	1992
Taxes	
Executive Director	$ 3,000
Director of Programs	2,200
Office Manager	2,000
Bookkeeper	1,500
Volunteer Coordinator	1,500
FUI and SUI	1,400
Worker's Compensation	550
Mortgage (A Baby's Place)	9,500
Rent	7,714
Utilities	26,000
Telephone	10,000
Building Maintenance	14,500
Insurance	5,000
Office Supplies	6,000
Printing	4,500
Postage	10,000
Equipment	
Owned	5,000
Leased	5,000
Maintenance	3,000
Conferences	4,000
Mileage/Travel	5,000
Advertising	3,000
Accounting	4,000
Consultants	15,000
Production Expenses	28,381
Educational Supplies	10,000
Financial Assistance	50,000
Other CBO's	25,000
Memberships	2,000
Products	2,250
Food	1,000
Miscellanous	2,000
Volunteer Devlop./Activities	1,500
Bank Charges	500
Permits	300
Production Personnel	1,000
NAMES Project Display	14,850
Photography	500
Gala Receptions	8,740
Carry-over	4,240
Total	$402,075

1991 CLIENT SERVICES DELIVERED

TOTAL $ PROVIDED: $46,732.83

CLIENT CONTACTS:		
	FINANCIAL ASSISTANCE	1437
	TRANSPORTATION	484
	CLOTHES CLOSET	240
	FOOD BANK	301
	STIPEND	393
	OTHER	2146
	COUNSELING	408

TOTAL CLIENT CONTACTS: 5303

DEATHS: (began gathering data in May, 1991) 34

NEW CLIENTS: 138

UNIDENTIFIED HIV+ CLIENTS SERVED: 180

UNIDENTIFIED NON-HIV+ CLIENTS SERVED: 55

BUS TOKENS PROVIDED: 241

1991 FINANCIAL ASSISTANCE TOOLS

RENT AND HOUSE PAYMENTS:	$18,250.02
UTILITIES:	10,004.42
FOOD:	940.02
TRANSPORTATION:	3,465.94
MEDICAL:	6,805.45
INSURANCE:	1,374.61
EDUCATION:	283.41
LEGAL:	465.26
CLOTHING:	95.00
	$41,684.13

Residents Benefit from Variety of Services Provided by 19 Groups

On October 12, 1990, Jerusalem House marked its first year as a home for people living with AIDS who otherwise would not have a place to live.

During 1990, 13 people lived at Jerusalem House. They included 12 males and one female. There were Caucasian and African-American residents. In addition, over 100 referrals were made to other permanent housing providers and emergency shelters.

Residents of Jerusalem House received a variety of social/health related services in addition to housing during 1990. Project Open Hand delivered over 3,600 freshly prepared meals to Jerusalem House residents.

A total of 95 days of in-home hospice care was provided by Hospice Atlanta and the Visiting Nurse Association. Grady Memorial Hospital's hospice program provided 125 days of in-home hospice care. AID Atlanta provided case management services to all Jerusalem House residents.

As part of the admissions process, all Jerusalem House residents become clients of the Georgia Department of Human Resources' Division of Rehabilitation Services and are eligible for all the agency's services such as counseling, psychological testing and rehabilitation training. Several Jerusalem House residents obtained employment after training during the year.

During 1990, the "Common Ground" day program of the Atlanta Interfaith AIDS Network provided a daily outlet for many Jerusalem House residents to interact in a supportive environment with other individuals living with AIDS.

The program included art therapy, free access to therapeutic disciplines such as healing imagery, dream work, massage therapy, traditional talk therapy, and music therapy. Planned field trips and a variety of other activities such as bowling, movies and swimming parties also were provided.

On Tuesday nights, the Shrine of the Immaculate Conception has provided dinners for many Jerusalem House residents.

Residents also received information about the treatment of AIDS from the Atlanta Chapter of the National Association of People with AIDS.

The AIDS Legal Project of Atlanta Legal AID provided legal services to Jerusalem House residents including the writing and filing of legal documents such as Last Will and Testament, Living Will, Durable Power of Attorney and Medical Power of Attorney. The AIDS Legal Project also assisted residents in filing for the new Medically Needy Waiver and in obtaining long-term disability income.

Organizations providing services to residents of Jerusalem House include:

Project Open Hand/Atlanta
Visiting Nurse Association of Metropolitan Atlanta/
Hospice Atlanta
AID Atlanta
Grady Infectious Disease Clinic
Georgia Department of Human Resources' Division
of Rehabilitation Services
Atlanta Gay Center
DeKalb Addiction Center
Shrine of the Immaculate Conception
Metropolitan Atlanta Chapter, American Red Cross
Atlanta Interfaith AIDS Network
Atlanta Chapter of the National Association
of People with AIDS
Grady Hospice
Project Prevail
AIDS Research Consortium of Atlanta
Fulton and DeKalb Departments of Family
and Children Services
U.S. Veterans Administration Medical Center
AIDS Legal Project
Grady Memorial Hospital

Report of Independent Public Accountants

To the Board of Directors, Jerusalem House, Inc.

We have audited the accompanying balance sheet of Jerusalem House, Inc. (a nonprofit organization) as of June 30, 1990 and the related statements of activity and cash flows for the year then ended. These financial statements are the responsibility of the organization's management. Our responsibility is to express an opinion on these financial statements based on our audit.

We conducted our audit in accordance with generally accepted auditing standards. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Jerusalem House, Inc., as of June 30, 1990 and the results of its operations and cash flows for the year then ended in conformity with generally accepted accounting principles.

Gifford, Hillegass & Ingwersen, P.C.

Gifford, Hillegass and Ingwersen, P.C.
Atlanta, Ga.
September 14, 1990

Jerusalem House Balance Sheet June 30, 1990

	ASSETS		
	Operating Fund	Property and Equipment Fund	Total
CURRENT ASSETS			
Cash and cash equivalents (Note A)	$13,918	$318,800	$332,718
Due from property and equipment fund	41,909		41,909
Current portion of pledges and awards receivable (Note A)	6,000	309,000	315,000
TOTAL CURRENT ASSETS	61,827	627,800	689,627
PROPERTY AND EQUIPMENT (Note A)			
Furniture, fixtures and equipment	8,819	35,540	44,359
Less accumulated depreciation	642	2,540	3,182
NET PROPERTY AND EQUIPMENT	8,177	33,000	41,177
OTHER ASSETS			
Pledges and awards receivable net of current portion (Note A)		267,200	267,200
	$70,004	$928,000	$998,004

LIABILITIES AND FUND BALANCE

	Operatiing Fund	Property and Equipment Fund	Total
CURRENT LIABILITIES			
Accounts payable	$ 2,642	$ 1,406	$ 4,048
Due to operating fund	-	41,909	41,909
Current portion of deferred revenue (Note A)	6,000	309,000	315,000
TOTAL CURRENT LIABILITIES	8,642	352,315	360,957
DEFERRED REVENUE, net of current portion (Note A)	-	267,200	267,200
COMMITMENTS (Notes B and C)	-	-	-
FUND BALANCE (Note A)			
Unrestricted	61,362	-	61,362
Restricted	-	308,485	308,485
TOTAL FUND BALANCE	$70,004	$928,000	$998,004

JERUSALEM HOUSE, INC. STATEMENT OF ACTIVITY For the Year Ended June 30, 1990

	Operating Fund	Property and Equipment Fund	Total
PUBLIC SUPPORT AND REVENUE			
Contributions	$ 70,458	$133,568	$204,026
Awards and grants	77,480	624,563	702,043
Interest income, net of $3,639 interest expense in property and equipment fund	1,106	7,807	8,913
TOTAL PUBLIC SUPPORT AND REVENUE	149,044	765,938	914,982
EXPENSES			
Program services			
Residential Services	18,651	2,540	21,191
Support services			
Fundraising	11,175	47,776	58,951
Management and general	69,718	30,485	100,203
Donation (Note B)	-	393,439	393,439
TOTAL EXPENSE	99,544	474,240	573,784
PUBLIC SUPPORT AND REVENUE OVER EXPENSES	49,500	291,698	341,198
FUND BALANCE AT BEGINNING OF YEAR	11,862	16,787	28,649
FUND BALANCE AT END OF YEAR	$ 61,362	$308,485	$369,847

JERUSALEM HOUSE, INC. NOTES TO FINANCIAL STATEMENTS June 30, 1990

NOTE A—SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

General Organization and Purpose: Jerusalem House, Inc. (the "Organization") was incorporated in the state of Georgia on August 2, 1988 as a nonprofit organization. The Organization provides residential services for homeless and destitute persons with AIDS at its facility in Atlanta. (See Note B)

Fund Accounting: To ensure observance of limitations and restrictions placed on the use of resources available to the Organization, the accounts of the organization are maintained in accordance with the principles of fund accounting. This is the procedure by which resources for various purposes are classified for accounting and reporting purposes into funds established according to their nature and purposes. Separate accounts are maintained for each fund. Accordingly, all financial transactions have been recorded and reported by fund group.

The assets, liabilities and fund balances of the Organization are reported in two self-balancing fund groups as follows:

Operating fund represents expendable funds that are available for support of the Organization's operations.

Property and equipment fund represent resources restricted for purchase and renovation of such items.

Pledges and Awards Receivable: Pledges and awards receivable represent amounts which have been restricted by prospective donors for use in operations or the purchase or renovation of land, building and equipment. Since these pledges and awards were not received before the end of the year, they have not been included in current support and revenue in the statement of activity.

Property and Equipment: Property and equipment are recorded at cost of fair market value, if donated, and are depreciated using straight line methods ranging from five to seven years based upon their estimated useful lives.

Tax Status: The Organization is exempt from income taxes under Section 501 (c) (3) of the U.S. Internal Revenue Code and is classified as an organization which is not a private foundation under Section 509 (a) of the U.S. Internal Revenue Code. Donations to the Organization qualify for the charitable contributions deduction.

Cash and Cash Equivalents: For purposes of the statement of cash flows, the Organization considers all investment instruments purchased with a maturity of three months or less to be cash equivalents.

NOTE B—DONATION OF LAND AND BUILDING

During the year ended June 30, 1990, the Organization purchased land and a building for its operations. Title to the land and building was subsequently donated to Metropolitan Atlanta Communiuty Foundation. The Organization now leases the and and building for $1 per year. The donation was made to enhance fund raising as well as to ensure that the property will consistently be used for community good.

NOTE C—COMMITMENTS

The Organization leases its administrative offices under an operating lease which expires in December 1992. Rent expense for the year ended June 30, 1990 amounted to $3,127. Future minimum lease payments at June 30, 1990 are as follows:

Year ended June 30:	
1991	$ 4,021
1992	4,342
1993	2,254
	$10,617

Capital Campaign $765,938
Year ending 6/30/90

Foundations	47.9%
Private Grants	23.6%
Individuals	9.4%
Businesses	8.0%
Government Grants	6.0%
Associated Organizations	4.0%
Miscellaneous	1.0%

Operating Fund $149,044
Year ending 6/30/90

Grants	38.3%
Individuals	33.8%
Associated Organizations	13.7%
Businesses	8.8%
Miscellaneous	2.9%
Special Events	2.6%

Organizations Supporting Jerusalem House 1988-1990

Business/Professionals

Affairs To Remember
American Society of Internior Designers
Architex International
Age of Travel, Macy's
Art of Printing
Arthur Anderson and Company
Atlanta Antique Exchange
Atlanta Market Center
B-52's
Ben Litowich and Son
Carlyle Fraser Employee Fund
Carnes Brothers
Checks N Balances
Clarence House
Columbiana Plastics
Coppers and Lybrand
D. Jacobs and Associates
Deloitte and Touche
Design Center of the Americas
Edward Fields, Inc.
Emory University Theatre Emory
Equifax, Inc.
Ernst and Young
First Atlanta, First and Last Trust
Formtech Enterprises
Furniture Exchange
Georgia Home Therapeutics
Glaxo, Inc.
Glenn Brown and Associates
Grant Thornton
Graphic Industries
Gretchen Bellinger, Inc
Griggs, Van Horn and Associates
Haas Club
Harris, Inc. (Dunk 'N Dine)
Harwell/Steffler Company
Hewlett Packard
Hinson and Associates
Hobe Sound/ Lamp Co.
I.B.M. Corporation
Ivan Allen Company
J. Dayvault and Associates
J.R. Scott and Associates
Jon Micheal Salon
Kirklands Janitorial Services
Kitchensmith
Kulman Brokerage
Lacey Champion Carpets
Marchant Industries
Medical Therapies
Micronetix
New Age Cabinetry
Occupational Training and Development
Olansky/Holzberg Dermatologists
Owens/Corning
Oxford Industries
Plaid Enterprises
Prince Street Carpets
Pollack and Associates
Scientific Atlanta
Southern Bell
Speake Garden Furnishings
The Porch
The Westin Lenox
Tigner Interiors, Inc.
Tower Financial Services
Troutman, Sanders, Lockerman and Ashmore
Tuxedo Catering
Victor Shargi and Associates
Winovich Associates
Wynfield House, Inc.

Foundations/Trusts

Allen Foundation
Atlanta Jewish Federation
Chatham Valley Foundation
Courts Foundation
Emsa Fund
English Memorial Fund
Exposition Foundation
Fox Foundation
Harland Foundation
Ida A. Ryan Charitable Fund
Johnson/Allen Memorial Fund
Katherine J. Murphy Foundation
Kent Richard Hofmann Foundation
LUBO Fund
Mary Allen Lindsey Branan Foundation
Meher Fund
Metropolitan Atlanta Community Foundation
Montag Family Trust
National Service Foundation
Nemo Foundation
Price-Gilbert Foundation
Rich Foundation
Robert W. Woodruff Foundation
Thomas Gilbert Jr. Foundation
Toll Gage Foundation
Tomlinson Foundation
Tull Charitable Foundation
Woodward Foundation

Religious Organizations

Ahavath Achim Synagogue
All Saints Episcopal Church
Atlanta Clergy and Laity Concerned
Atlanta Reform Synagogue
Catherdral of St. Philip
Catholic Archdiocese of Atlanta
Church of the Epiphany
Corpus Christi Charities
Episcopal Charities Foundation
Good Shephard Episcopal Church
Grace Lutheran Church
Holy Spirit Catholic Church
Jesus Christ Center of Truth
Lutheran Ministries of Georgia
Oakhurst Baptist Church
Peachtree Christian Church
Rev. Vincent Mulvin Memorial Fund
Sacred Heart Catholic Church
St. Anne Catholic Church
St. Bartholomew Episcopal Church
St. Benedict Catholic Church
St. Bernadette's Catholic Church
St. Francis Catholic Church
St. James Episcopal Church
St. John Newmann Catholic Church
St. John Catholic Church
St. Johns Home
St. Lukes Episcopal Church
St. Matthews Episcopal Church
St. Michael's and All Angels Episcopal Church
St. Paul of the Cross
St. Pius X Women's Club
The Temple
Temple Beth David
Temple Sinai
Trinity Presbyterian Church

Government Agencies

City of Atlanta/CDBG Program
Coffee County Health Department
Columbia County Health Department
Community Health Section, Georgia Department of Human Resources
DeKalb County Finance Department
DeKalb County, RPCA
Georgia Public Health Association
Georgia Residential Finance Authority
Glascock County Health Department
Jenkins County Health Department
Lab Employees, Department of Human Resources
Richmond County Health Department
Rome Public Health Department
State of Georgia, Department of Human Resources
Toombs County Health Departments
U.S. Department of Health and Human Services

Associated Organizations

100 Black Men of Atlanta
American College of Emergency Physicians
Atlanta Couples Together
Beulah Payne School
Boys and Girls of Fall Bowling League
C&S Care and Share Club
DAISY Youth Clinic
Georgia Nurses Foundation
Georgia Power Club of Hearts
Georgia Southern University
Goldkist/Cotton States Choir
Helping Hands of Atlanta
Junior League of Atlanta
Once Only Club, Georgia Federal Employees
Panther Levi/Leather Inc.
Planned Parenthood of Atlanta
St. Joseph's Mercy Care Corporation
TC Dance Club
TDA Atlanta
Tri-Cities High School
United Way of Metropolitan Atlanta

In addition, over 600 people contributed to both the General Operating and Capital Funds.

January 11, 1996

To the Manager of Public Relations / Poster Distribution

Dear Aids Educator,

As private individuals in Germany and the Netherlands we are assisting various public archives in Europe as well as in the United States in building Aids poster collections. With Aids Information Document Center, Bern, Switzerland we are planning to fuse our collections into an already existing slide catalogue project and possibly making them available on computer disk as an image bank of the most comprehensive collection of international Aids poster images to concerned organizations worldwide.

In order to have as many original posters as possible represented and preserved in each connected archive, we would like to request you to **please send us 5 copies of every poster on Aids of your present as well as past campaigns**.

In these collections we include **all** posters which are Aids related: preventive educational ones, as well as those for events like benefits, concerts, exhibitions, etc.

Should sufficient stocks of older posters not exist, even a single copy or any posters that you might have of other organizations or countries, would be a valuable contribution to the completion of this project.

Since it may also be in your interest to have your posters preserved under archival conditions for future projects like exhibitions and publications, would you please send your posters at non-profit productions prices plus postage. One copy of each poster we have received until present is included in Hoover Archives, Stanford University. They have received so far around 1,700 Aids posters from us in exchange for other posters.

To save on postage, you can send the posters to the following temporary address in the United States **until February 8th**:

Thomas Hill
1236 McAndrew Road
Ojai, CA 93023
805-646-8505

For shipments after this date, please keep our permanent address on your mailing list:

A Mijwaart
Huntum GA
36 32 XK Loenen/Vecht
Holland.

Thank you for your cooperation and help in what we consider an important project.

Sincerely yours,

Th. Hill

Thomas Hill

Jan./Feb./Mar., 1996

AIDS TASK FORCE OF ALABAMA

ALABAMA SURVEILLANCE INFORMATION As of August 11, 1995

•Number of AIDS related deaths: 2,022 •Number of AIDS cases: 3,418

No. 1

A non-profit organization dedicated to state-wide HIV/AIDS prevention and housing for persons living with AIDS.

NONDISCRIMINATION POLICY

The AIDS Task Force of Alabama will not discriminate on the grounds of race, ethnicity, color, gender, familial status, sexual orientation, national origin, age or handicap. All persons are welcomed to any ATFA Program. The AIDS Task Force of Alabama is an equal opportunity employer.

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Joe Jemison, Case Manager
Loren Peters, HIV/AIDS Community Volunteer Coordinator
Peter Anaya, Community Health Outreach Worker
Geneo Boyd, Community Health Outreach Worker
Gretchen Jones, HOPWA/Shelter Care Plus Coordinator (Jesuit Volunteer)
Mary Kay Swartz, Grants Assistant (Jesuit Volunteer)
Wanda Boswell, Transportation Coordinator (National AIDS Fund Americorps member)
Pat Noling, Housing Coordinator (National AIDS Fund Americorps member)
Fred Ryan, Americorps Member, UAB School of Public Health

THE ROBERT WOOD JOHNSON GRANT has made ATFA the home operating base of a Community AIDS Volunteer Coordinator position. After an extensive interview process, the candidate chosen for the job was Loren Kendall Peters. Mr. Peters holds a B.S. from University of the Ozarks and a Masters in Public Health from UAB. He comes to ATFA with a wealth of experience in the fields of Public Health, Mental Health, Education, Recreation Therapy, and Religion. As a Public Health professional, he has served as an educator, planner, and researcher. He has played instrumental roles in grant-writing for agencies such as school-age child care, rural health outreach, and an education network. Mr. Peters is also a candidate in the process toward ordination in the Episcopal Church.

Although the Volunteer Coordinator Position provides an office base for Mr. Peters at ATFA in Ensley, he will be working with all of the AIDS agencies in town to coordinate and utilize volunteers.

A Letter From The President

The 1996 Board of Directors referenced in this newsletter is a talented and dedicated collection of persons from business, religious, social service, health care, and community organizations. ATFA is very fortunate to have both returning and new board members as a part of the ATFA family. We welcome them all and thank them in advance for their commitment of time, thoughtfulness, and hard work.

The pleasure of serving on the board of an agency dedicated to helping persons is that we all feel good about the work we are doing. ATFA is successful at reaching our goals when:

- we provide a family a place to live,
- we work with our associates across the state to win federal grants which directly benefit the infected population,
- we realize that over 2,000 individuals have been directly assisted with their rent across the state due to ATFA's efforts,
- we provide housing to over 100 persons who have no other place to live,
- we provide legal assistance or advocacy for someone whose employer terminates them simply because they live with HIV, and when
- we recruit a solid, dedicated staff who fulfills all of the obligations that a budget in excess of $2 million requires.

The challenges that face us include the knowledge that the combination of all the resources still do not meet all of the needs of the population. Furthermore, the challenge is always with us of depending on government grants as opposed to a balanced funding stream.

As we enter into a new year, I ask you to consider the ways you can support our efforts through contributions of furnishings, funds, time, or ideas. All of these gifts are welcome.

Thanks to all of you for the support and participation you have given to ATFA over the past year. Your involvement has contributed to our success in serving the HIV community.

Sincerely,

Thomas E. Baddley, Jr., Esq.
President, Board of Directors

Robert Wood Johnson Foundation Funds

HELP BIRMINGHAM AIDS ORGANIZATION

The AIDS Task Force of Alabama is one of a group of churches and nonprofit organizations in Birmingham chosen as part of a Faith in Action project by the Robert Wood Johnson Foundation. The $25,000 grant will assist religious organizations and social service agencies in creating community volunteer service projects to serve families, the elderly, and children. This year's theme is "Working Together to Help Answer the Need."

ATFA executive director Randall Russell says of the program, "While medical services for HIV-infected persons in Birmingham are excellent, we want to help people living with HIV receive as much home-based care as possible. This Faith in Action grant will help us reach out to our neighbors in need."

The Robert Wood Johnson Foundation, based in Princeton, N.J., is the nation's largest private philanthropic organization devoted to improving health care through grant-giving. Faith in Action was established two years ago. The $25,000 grants are start-up funds targeted to tax-exempt social service agencies and health care providers such as hospitals, clinics, and substance abuse programs. The Foundation expects to fund 800 Faith in Action grants totaling $20 million over the next two years. Recipients must obtain matching funds locally in order to continue projects in the future.

In Birmingham, the project will work with a coalition of area churches and nonprofit organizations. Volunteers will provide transportation to medical appointments, assist with meal preparation, and offer companionship. Other organizations joining the project include:

Birmingham AIDS Outreach	AIDS in Minorities	1917 Clinic
First Presbyterian Church	National Episcopal AIDS Task Force	
St. Andrew's Foundation	Southside Baptist Church	Episcopal Church of the Advent
Roman Catholic Diocese of Birmingham	AIDS Care Team	AGAPE Foundation

For information on the Birmingham Faith in Action project or to volunteer, call (205) 592-2437 or contact the project at P.O. Box 55703, Birmingham, AL 35255. For information on how to start your own Faith in Action program, contact Dr. Kenneth Johnson, Executive Director, Faith in Action, at (914) 331-0016.

ATFA Has New Director of Programs

IOn December 1, Mr. Will Hodge joined the ATFA staff as the Director of Programs. Mr. Hodge has a background of diverse experiences in community leadership and has been active in AIDS education and prevention for over a decade.

A Baptist minister, he was part of the front line within the clergy of educating churches about the vital issues of AIDS prevention and education. He holds an M.S.W. from University of Alabama- Tuscaloosa, as well as an M.Div. in Pastoral Care and Counseling from the Southern Baptist Theological Seminary. He did a clinical Pastoral Education Residency at the Baptist Medical Centers. In addition, he has done post-graduate work in counseling at UAB, and is presently working on his Ph.D. Mr. Hodge lives in the Vestavia area. His wife Pat is the principal of the Mountain Brook elementary school.

Will began caring for individuals diagnosed with AIDS as a chaplain at University Hospital. He remembers those early days of the epidemic as being a time of misinformation and confusion about the disease. He recalls a woman coming to speak with him, bewildered about watching her spouse die. With a puzzled expression, she said, "They say he has something called 'AIDS'." Mr. Hodge believes that misunderstandings continue to exist even in this, the beginning of the disease's second decade. He says, "People still tell me that they don't think they're being told everything they need to know about AIDS." He still sees prejudice as the biggest obstacle to many individuals when it comes to living, working, and serving persons with AIDS. Years of experience with both adults and youth groups has taught him that denial is a prevalent emotion: "There are people out there who still want to think of AIDS as a gay disease. It's hard to believe that this is still a hurdle."

He has always displayed a strong commitment to utilizing religious communities in AIDS education, but his committee work has not stopped there. He has served on the education committee for the Red Cross for six years, and since 1986 has served several terms on the ATFA board. Working with ATFA drew him to addressing yet another dimension of the AIDS epidemic —housing. He gained experience in finding housing for needy individuals through a program he helped to implement at the Birmingham Baptist Association. On a sliding scale model, they operated 14 apartments for people who could not afford housing when they came to Birmingham to care for hospitalized family members.

Mr. Hodge is excited about working with the growing resources and existing challenges of ATFA. He describes the unique nature of the agency, "While we are not a hospice, we are able to provide housing. While we are involved in, and interested in, the well-being and health of our clients, we are not the front-line caregivers. I think that what we do best is facilitate care through other agencies."

He comes to ATFA during a time of major growth in staff and resources. He says that he is impressed with the staff, particularly the volunteers' assistance. He notes that ATFA faces challenges in outstripping our capital support, "Our equipment is not yet up to speed with our staffing." If his first month is any indication, ATFA will take great steps in using its staff potential under Mr. Hodge's direction.

A Letter From The Executive Director

Greetings to all of our supporters and readers!

On behalf of the staff and Board of Directors I wish you all a peaceful and happy new year.

As the U.S. Congress determines what to do with the 1996 budget, I want to remind all of us that advocacy does work. In 1995, Alabama rallied with ASONA (AIDS Service Organization Network of Alabama) and sent more faxes, phone calls, and messages to our federal and state delegations than ever before. Indeed, on a couple of issues at the federal level, Alabama led the nation with comments about possible cuts to valuable HIV-funding sources.

The federal government's response to AIDS involves several different U.S. Departments. Research funding is made available through the National Institutes of Health, care dollars through Health and Human Services and Housing and Urban Development, and education money through the Centers for Disease Control, to name a few. These funding entities include hundreds of dedicated workers and some true leaders who have helped provide more funds to care for infected persons and prevented some new infections from occurring thanks to their prevention efforts. These agencies provide funds to non-profits to design programs that best match the needs at the community level.

Congress may not allow these programs to continue or to grow to meet the new demands of those persons newly infected. As science discovers the combinations of medications and therapies that can prolong the life of an infected person, more people are living longer, and requiring more resources, not less. Some in Congress have said that the recent government shutdowns prove that since the world did not stop turning, the need for less government is proven.

We need to make sure that we tell our elected officials how we feel and what we know to be true about government-directed programs for persons living with HIV. While there will never be enough, the resources that exist now are making a difference and we need to communicate just how much. If you are interested in helping with this process, call me at 781-6448, and I will be glad to direct your efforts and add you to our growing legislative advocacy list.

Thanks to all of you who help ATFA. We appreciate all of your support and look forward to working with you in the new year.

Sincerely,

Randall H. Russell
Executive Director

"UMOJA SASA!": UNITY NOW!

In the Swahili language, "Umoja Sasa!" means "Unity Now!" The Umoja Sasa Product Corporation© in conjunction with Health Departments throughout the country has launched a national campaign to encourage African American communities to "protect the blood." The project emphasizes unity within the communities to "stop the killing...the drugs...breaking up our families.....and to stop the spread of HIV/AIDS in our community." ATFA will incorporate "Umoja Sasa!" by distributing pamphlets, posters, T-shirts, and condoms printed with these slogans. The literature urges partners to talk to each other about using latex condoms. It offers a reminder that "people who carry the AIDS virus don't always look sick, so you just never know who might have it." The Alabama Department of Public Health has provided ATFA with the information and materials needed to implement the campaign.

ATFA Staff Added

This fall, ATFA began its outreach program with the addition to our staff of two full-time outreach workers, Peter Anaya and Geneo Boyd. Their positions at ATFA were created by HUD's Supportive Housing Grant over a period of three years.

In the past two months, Peter and Geneo have been researching the demographics of the HIV/AIDS epidemic in Jefferson County, and are also networking with service providers. The goal of the outreach program is to seek out individuals who have HIV/AIDS, and to offer them different options for housing. Their outreach efforts will focus on places where the homeless population congregate and seek services, such as street, parks, jails, churches, shelters, and other service providers.

Peter Anaya comes to us with over twenty years of experience working with youth, adults, and families in a variety of social services. Recently, Peter provided HIV/AIDS education, prevention, and training in Hawaii where he lived for the past twenty years. Through the University of Hawaii as a Community Health Outreach Worker, he played a major role in developing and implementing the first HIV/AIDS research and outreach programs for the island of Kauai.

A native of Birmingham, Geneo Boyd comes to outreach work with experience in advocacy for homeless, and HIV+ populations. He formerly worked in Atlanta, Georgia, for an agency that works for SSI benefits for homeless individuals with HIV/AIDS. He attributes his involvement in outreach to "an overwhelming concern about the prevalence of HIV/AIDS among African-Americans."

The estimated number of homeless in Birmingham is 2200 persons. If the projected numbers of potentially HIV+ homeless are on target, then ATFA's new outreach program may be successful in significantly narrowing the number of homeless in the area. Our housing programs may certainly provide viable alternatives to the streets.

HIV/AIDS Prevention... Can You Help?

Imagine a world without AIDS. An unrealistic thought? I don't think so. The University of Alabama at Birmingham has been an active participant in the development and testing of potential AIDS vaccines since 1994. The University is one of six Vaccine Evaluation Units in the U.S. designated by the National Institutes of Health (NIH) to evaluate safety and immune response to AIDS preventive vaccines.

All AIDS vaccine studies require healthy, HIV-negative volunteers between the ages of 18-60 to make a commitment to participate for the duration (18-24 visits spread out over a two-year period) of the study. Prior to entertaining the study, all volunteers will be counseled and screened to determine eligibility. After vaccine testing begins, volunteers are frequently evaluated with interviews, physical examinations, and laboratory tests to monitor vaccine safety and immune response.

Of special note, a volunteer cannot become infected with HIV from the vaccine itself. No live or altered HIV is used in the development of a vaccine.

The identity of each volunteer is confidential, and all volunteers are identified by code number rather than by name. All identifying information and records are stored in a locked file, and only persons directly involved with the vaccine program have access to this information.

So, why should someone consider volunteering for a preventive vaccine study? Information gained from these trials may lead to a greater understanding of the immune response to vaccination agaist the AIDS virus. Because the control of AIDS will likely depend on the development of a safe and effective vaccine, participation in a vaccine trial could potentially be of great benefit to mankind. In addition, volunteers will receive free physical examinations and laboratory tests that will evaluate their general health and immune system status.

So, you may not be able to donate a lot of dollars to the cause, but you may be able to give something more worthwhile of yourself and your time. A few hours a month during the trial periods all that is required.

If you are interested in volunteering or have any questions, call Rick Meriwether at 975-2839 or 1-800-822-8816 (outside the greater Birmingham area) at the Alabama AIDS Vaccine Evaluation Unit.

The Cooperative Spirit at AGAPE House

The term "Agape" stems from the ancient Greek, meaning "selfless love." In my opinion, it is this type of "love" which gives a person the impetus to pursue the type of work provided by almost any service agency. It is the concern for people other than ourselves, especially those who are less fortunate or needy in some way, that enables individuals to work for the betterment of not only particular clients in housing programs such as ATFA's, but also for society as a whole. It is this special type of love that makes AGAPE House a home for residents dealing with ups and downs of living with HIV. Without the cooperation of residents and the many agencies here in Birmingham that are involved in the day-to-day operations here at AGAPE House, ATFA would never be able to keep this permanent housing facility up and running.

Opening and maintaining an apartment complex takes more than just administration — it takes cooperation and coordination between residents, ATFA staff, security, volunteers, and health care agencies. It is through teamwork that AGAPE House becomes a home. Residents have formed a tenant council to address issues of concern and meet with ATFA on a monthly basis to keep updated on AGAPE House activities and policies. With all the plentiful donations and work of many gracious individuals and organizations within the community, AGAPE House has been very fortunate. Everyone here thanks you for all your hard work and bountiful contributions of household items, holiday decorations, gift boxes, and wonderful food!!

Many of the residents here in AGAPE House are healthy and living independently. However, there are others who require extra care by home health aids and sitter services. Since ATFA is not a service provider, we rely on service agencies like AmeriCorps, CareTenders, etc. to provide the necessary health care to our residents when they are ill. The work that these agencies provide plays an intricate role in allowing our residents to remain in the comforts of their own home during a period of illness. With everyone's hectic schedules and the sometimes urgent nature of the resident's health, it is sometimes frustrating to coordinate service at the drop of a hat. But by working together and keeping the lines of communication open, we are able to get what is needed and ATFA is extremely thankful for that. We appreciate all the work and dedication on part of service agencies as well as the security guards on duty that must take care of such situations when an ATFA staff member is not on site. It is this cooperative atmosphere that enables AGAPE House to function smoothly.

AGAPE House is more than just an apartment complex. It is a unique home for many individuals in need of that special "agape" love. It is the cooperation and coordination of the many social service agencies, volunteers, security, and staff here at ATFA that have truly made AGAPE House a home.

—by Gretchen Jones, Jesuit Volunteer/ AGAPE

Furniture Need Continues

The need for furniture continues to exist at ATFA for use in our transitional housing programs. We anticipate opening up many new housing units in the Birmingham area during the early part of 1996, and these houses and apartments will all need to be furnished. All types of furniture and household items are needed with an emphasis on useable mattresses, bed frames, working appliances and dinette sets in good condition.

Our ability to pick up these items from the donor is limited, but we will try our best to arrange some way to get them from you if you are unable to deliver them to the ATFA office in Ensley.

Please contact Housing Coordinator **Patrick Noling** at **781-6448** and schedule a time for your furnishings to be dropped off or to make arrangements to have them picked up.

AIDS TASK FORCE OF ALABAMA

1996 ANNUAL HOUSING CAMPAIGN

Your Tax-deductible donation will go directly towards housing persons living with AIDS. Less than 15% of any contributed dollar goes towards administration.

YES, I WILL SUPPORT ATFA'S HOUSING PROGRAMS.

❑	$15	Student	❑	$500	Carpenter
❑	$50	Individual	❑	$1,000	Architect
❑	$100	Family	❑	$2,500	Developer
❑	$250	Patron	❑	$5,000	Owner

CONTRIBUTOR BENEFITS

- ✔ All levels receive ATFA's newsletter
- ✔ Architect and above will have name placed on the AGAPE plaque
- ✔ Owners and above will receive custom designed programs including educational materials and programs free for employees

Corporation or Individual Name*_____

Contact Person _____

Addresss _____

City _____ State _____ Zip _____

Telephone (Day) _____ Telephone (Evening) _____

*As is to be listed on the plaque at AGAPE House.

❑ My check is enclosed. Make check payable to the AIDS Task Force of Alabama

❑ Please bill my credit card. MC or VISA. Card #_____ Exp._____

For your convenience, you may call ATFA with your Credit Card Number or Pledge at 1-800-592-2437 or 781-6448
Send check or Money Order to: P.O. Box 55703, Birmingham, AL 35255

HELP BUILD A BETTER FUTURE FOR THOSE AFFECTED BY HIV AND AIDS IN ALABAMA. CONTRIBUTE GENEROUSLY TO ATFA'S ANNUAL HOUSING CAMPAIGN.

Thank You!

ATFA extends a warm post-holiday thank you to all of those who helped to organize our "Deck the Halls" silent auction. The event took place at the Birmingham Art Association on December 2, 1995 and raised a considerable sum for our housing programs. The event offered holiday wreaths decorated by various local designers, as well as artworks, gift items, and recreation and vacation packages. ATFA staff, board members, and supporters enjoyed each other's company and holiday refreshments throughout the afternoon, and welcomed passersby from the Birmingham Art Walk, a tour of the downtown galleries which took place the same day.

We extend special thanks to Adventure Travel and Vacation Express for the Cancun Vacation, and to the following for their support and contributions:

Alabama Crown Distributing
Alexander's Coiffures
Angel Hair
Arctic Ice Company
The Arrangement
Birmingham Art Association
Bill Johnson Floral Designs Etc.
Stephen Broyles
Bruno's
Renarda Bryant-Lane
Linda Cebulski
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Karen Farabee
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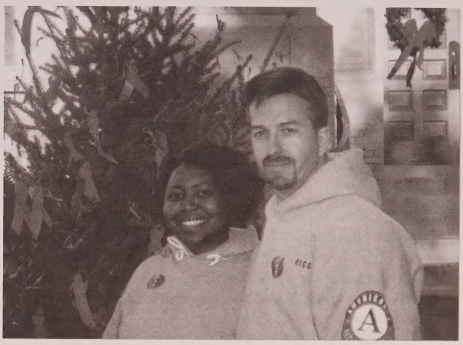
Highland Bar & Grill
Holiday Inn Redmont
International Wines
Inverness Golf
Margaret Jones
Les Affaires
Dee Dee Lyons
John McDole
Richard Meriwether
Park Lane Florist
Linda Potts
Pro Golf Discount, Inc.
Ritz Florist
Sharon Shaw
Silkwood
Southern Living
Therapeutic Skin Center
Tracy's
Richard Tubb
The Tutwiler
Wanda June's
Alan Woellhart
The Wynfrey Hotel

Executive Assistant Shirley Hay chats with board member Wendy Crew at "Deck the Halls," our holiday silent auction.



AFTA's National AIDS Fund Americorps members Wanda Boswell and Pat Noling pose in front of the "Care Tree" on World AIDS Day.

AIDS TASK FORCE OF ALABAMA

TASK FORCE OF ALABAMA
PO Box 55703
Birmingham, AL 35255

Non Profit Organization
U.S. POSTAGE PAID
BIRMINGHAM, AL
PERMIT NO. 3712

Shirley Lambert
911 G Valley Avenue
Birmingham, AL 35209

Ability Life Trust
668 N. Orlando Avenue, Suite 108, Maitland, FL 32751
1-800-632-0555 24-Hours
1-407-629-0599-Fax

PERSONAL

Full Legal Name _____

Mailing Address _____

Home # _____ **Work #** _____

D.O.B. _____ **Place of Birth** _____

SS # _____ **Drivers License #** _____

Marital Status ☐ **Married** ☐ **Single** ☐ **Divorced** **Any Bankruptcy** ☐ **Yes** ☐ **No**

Employer _____ **Date last worked** _____

LIFE INSURANCE

Life Insurance Co. _____ **Type of Coverage** ☐ **Group** ☐ **Individual**

Policy # _____ **Certificate #** _____

Face Amount _____ **Date issued** _____

Premium Amount _____ **Premium Mode** _____

Who pays premiums _____ **Are you on waiver of Premium** ☐ **Yes** ☐ **No**

Any loans on policy ☐ **Yes** ☐ **No** **Beneficiary of Policy** _____

If part of a group provide name of contact regarding policy _____

_____ **Phone #** _____

Any other polices in force? ☐ **Yes** ☐ **No** **Insurance Co.** _____

MEDICAL

Primary Doctor _____ **Phone #** _____

Address _____ **Fax #** _____

Date diagnosed HIV _____ **AIDS** _____

Last known T-Cell count _____ **Date** _____

Brief description of your medical condition _____

_____

_____

_____

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1-800-632-0555 24-Hours
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AUTHORIZATION TO RELEASE MEDICAL RECORDS

I hereby authorize any physician, medical practitioner, hospital or medically related facility, insurance company, The Medical Information Bureau or other institution or person having any records, charts, X-rays, laboratory work, or similar information or knowledge of me or of my health, including but not limited to information relating to AIDS/ARC/HIV, to release such information to Ability Life Trust or its authorized representative(s). I understand that information obtained will only be released to Ability Life Trust or its authorized representative(s) or as lawfully required. I agree that this authorization is valid for forty-eight (48) months from the date hereof, that a photocopy or facsimile of it is as valid as the original and that I may request a copy of this authorization.

I acknowledge receipt of the Terms and Conditions and Notice of Disclosure.

_____
Signature

_____
Typed or Printed Name

STATE OF _____)
)SS
COUNTY OF _____)

SWORN TO AND SUBSCRIBED before me this ____ day of _____, 19__,
by: _____
(Seller of Policy)

_____
Notary Public

Print Name

Personally Known: _____
Produced Identification: _____
Type: _____

My Commission Expires:

(SEAL)

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668 N. Orlando Avenue, Suite 108, Maitland, FL 32751
1-800-632-0555 24-Hours
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AUTHORIZATION TO RELEASE POLICY INFORMATION

I hereby authorize _____
the issuer of that certain Policy Number _____
owned by _____
and insuring the life of _____, (the Policy), to release to Ability Life Trust information, forms, riders of amendments concerning the Policy. I agree that this authorization is valid for forty-eight (48) months from the date hereof, that a photocopy or facsimile is as valid as the original and that I may request a copy of this authorization.

I acknowledge receipt of the Notice of Disclosure of Information..

_____
Signature - Owner of Policy

_____
Typed or Printed Name

STATE OF _____)
)SS
COUNTY OF _____)

SWORN TO AND SUBSCRIBED before me this ____ day of _____, 19__,
by: _____
(Seller of Policy)

_____
Notary Public

Print Name

Personally Known: _____
Produced Identification: _____
Type: _____

My Commission Expires:

(SEAL)

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Ability Life Trust
668 N. Orlando Avenue, Suite 108, Maitland, FL 32751 1-800-632-0555 24-Hours

TERMS AND CONDITIONS

Notice of Disclosure

The undersigned warrants and represents that all information contained in this application is true and correct to the best of his/her knowledge.

If current medical records are not available, the Insured consents to be examined by Ability Life Trust, Inc., or it's medical representatives.

The undersigned consents to and authorizes the release of any information requested by Ability Life Trust, Inc., from any third parties, including my employer(s) and or any credit reporting agency.

The undersigned herein includes a **PHOTOCOPY OF PICTURE IDENTIFICATION** and swears and warrants that he/she is, in fact, the person so identified.

There may be financial alternatives to the discounted sale of life insurance policies. You should review all options, such as an "Accelerated or Living Benefit Option," which may be offered by your insurer.

There are "Tax Consequences" to selling your insurance policy. Presently, the sale of a life insurance policy is a taxable event. We recommend that you obtain tax advice and counsel with regard to the sale of your life insurance policy.

Selling your life insurance policy may cause an interruption in your receipt of public assistance benefits. We recommend that you obtain further information regarding this possibility.

The Insured/Owner has the absolute right to rescind the discounted sale of his/her life insurance contract within fifteen (15) days of execution and any waiver of the right of rescission is void. To exercise the right of rescission, the Insured/Owner must return the full discounted payment with the statutory period.

An original or copy hereof may be used by Ability Life Trust, Inc., or it's authorized representatives to request and obtain information. The undersigned hereby agrees that a photocopy of this authorization shall have the same authority as the original.

_____ _____

Signature of Applicant Printed Name

STATE OF _____)
)SS
COUNTY OF _____)

SWORN TO AND SUBSCRIBED before me this _____ day of _____, 19___. by

_____ _____

(Applicant) Notary Public

_____

Print Name

Personally Known: _____
Produced Identification: _____
Type: _____

My Commission Expires:
(SEAL)

© 1995 Ability Life Trust, Inc.

Mission Statement

Our mission at Ability Life Trust is to not only simplify the complicated and time consuming process of a viatical settlement but to ensure that you will have the ability to continue leading a rich and productive life.

Ability Life Trust offers people with up to five years of life expectancy the option of selling their life insurance policies for up to 80% of the face value in one lump sum of cash. All individual policies and most group policies can be purchased. We represent the insured, not the investor, and have consistently obtained the highest settlement possible for our clients.

ABILITY LIFE TRUST, INC.
668 N. ORLANDO AVE., SUITE 108
MAITLAND, FLORIDA 32751
TEL: (800) 632-0555
FAX: (407) 629-0599

ABILITY Life TRUST

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e-mail ability@magicnet.net
http://www.magicnet.net/ability

MEMBER NAPWA
NATIONAL ASSOCIATION OF PERSONS WITH AIDS

Common Questions

1. *Why should I sell my life insurance policy?*

A terminal illness deprives one of the ability to earn an income and further depletes other financial resources. Our clients utilize these funds to continue receiving quality health care, to visit a family member or take a memorable vacation, but most of all, to continue to live with financial independence and dignity.

2. *How can Ability Life Trust help me?*

Our personal staff eliminates the stress, paperwork, follow-up time and attention it takes to maximize the amount of money you receive. By completing our simple application, Ability Life Trust will use its expertise and the opinions of independent medical consultants on your behalf. We obtain all the necessary verification to represent you to our many benefactors.

3. *How much can I expect to receive?*

Through Ability Life Trust you can always expect us to obtain the highest percentage possible. You will receive up to 80% of the face amount of your policy. The amount is determined by such things as the quality of your life insurance, the size of your policy, life expectancy and the premium amount.

4. *What size policies can be purchased?*

Ability Life Trust will help anyone facing a life threatening illness to obtain funding regardless of how small or large the policy is.

5. *How do I know if I qualify?*

- The policy must be issued by an insurance company highly rated by A.M. Best.
- The policy may be individually owned or a group; however, if a group policy it must be:
  - Absolutely assignable
  - Convertible to an individual policy without incurring a renewed contestability period.
- Policy must be at least 2 years old.
- The insured applicant must have a medical diagnosis confirming a life expectancy of generally less than 48 months; however, sometimes as long as 60 months.

6. *Am I responsible for paying the premiums after I sell my policy?*

No. The purchaser is responsible for paying all future premiums.

7. *Are there any costs for your service?*

None whatsoever. No fee is ever charged to the client for the services performed by Ability Life Trust.

8. *How long does the process take?*

Each individual case is unique and depends on the promptness of your doctor and insurance company in returning the required forms. The entire process usually takes between 3 to 6 weeks. We know time is of the essence and our professional staff will expedite each file immediately upon receiving your application.

9. *Can I change my mind after I sell my policy?*

Yes, we allow a fifteen day "grace period" once you have received your funds through a bank wire or certified check.

10. *How do I get started?*

Just call us at 1-800-632-0555 for a free information kit and we will answer any further questions you might have. All information is held in the strictest confidence to safeguard your rights and privacy.

ABILITY Life TRUST
1177 LOUISIANA AVENUE, SUITE 212
WINTER PARK, FLORIDA 32789
A VIATICAL SETTLEMENT COMPANY
TOLL FREE 1 800-632-0555

Thursday, January 11, 1996

AIDS Care Team
MCC
5117 1st. Avenue N
Birmingham, AL 35212

Dear Caregivers,

It was a pleasure speaking with you on the phone today and we do understand how valuable your time must be.

You assist people who are HIV positive. So you are well aware that this disease consumes one's energy and depletes one's financial resources. To provide the basic necessities of life and quality health care, money is essential.

Ability Life Trust offers people living with a terminal illness the option of selling their life insurance policy, often one of their last tangible assets, for cash.

The process of selling one's life insurance need not be complicated or time consuming. Our professional staff is available 24 hours to assist your client in the application process and represents them during the negotiation and sale of their policy at no cost.

Our service is always prompt, courteous and completely confidential. Our goal is to obtain the highest settlement payment as quickly as possible in order for them to maintain financial independence and dignity. Our many different benefactor groups go through a bidding process in order for the PWA to obtain top dollar in a timely fashion.

We assist anyone facing a terminal illness no matter how long their life expectancy is and will work with any type policy no matter how large or how small.

Please take a moment to review the enclose brochure and application to familiarize yourself with this simple but revolutionary concept. If you have any questions or would like to receive more brochures, applications or information, we welcome your call.

Sincerely,

Koko Guevarra
Client Services

Savage Grace

BY MARK MATOUSEK

While thousands of lives have been shattered by AIDS, the disease has also sparked tremendous political and spiritual transformations.

"When thought is obliged by an attack of physical pain, however slight, to recognize the presence of affliction, a state of mind is brought about, as acute as that of a condemned man who is forced to look for hours at the guillotine that is going to cut off his head. Human beings can live for twenty or fifty years in this acute state. We pass quite close to them without realizing it. What man is capable of discerning such souls unless Christ himself looks through his eyes?"

—Simone Weil

The night I became infected with HIV, there was a thunderstorm in the valley where I lived. I drove around my ex-lover's block, steering past trees struck down by lightning, squinting through the rainy windshield, debating whether or not to knock on Bob's door for sex. I remember a feeling of danger—enhanced by the weather, I'm sure, and the nasty thrill of seducing a person you no longer love. After we'd finished our violent, sloppy encounter, I walked back into the downpour feeling spent and exhilarated.

Six years later, when Bob got sick, we talked about what AIDS was like. "You're not going to believe me," he said, "but I've never been happier in my life."

I studied his face for irony. "But you might die," I said.

"Worse things could happen." Bob was serious. Something had shifted in him since his diagnosis. He was softer now, more circumspect. The mentor relationship we'd had since I was 18, when he, a successful show business mogul, plucked me from juvenile delinquency and showed me how to clean up my act, was finally becoming a friendship between equals. With his arrogant mask beginning to melt, I was seeing my former hero for who he was, a man without the trappings of movie-star clients and limousines, without the impenetrable shields of confidence and control that had made him a success. Stripped of all that, Bob was finally naked, accessible, human. AIDS had provided him with an exit from a fast-track life he had long grown weary of and permitted him to spend his days with the things he loved most: Schwartzkopf singing "The Four Last Songs" and the Navajo art of R.C. Gorman.

Satisfying the needs of his soul, Bob had also been spurred by illness to explore spirit. A diehard atheist, he'd begun to think about his relationship to God, to investigate wisdom literature, to ask questions about the nature of existence. Much of this education was taking place under the tutelage of a newfound friend, death-and-dying pioneer Stephen Levine, whose many books were stacked on the nightstand. "It's like walking through the looking glass," Bob mused, referring to spirituality. "Like falling down the rabbit hole and wondering which side is crazy, the flat old world or the wonderland. I'm not sure what I believe anymore, everything's turned so fascinating. Awesome, in fact."

The photo at right, *Don and His Mother*, was taken by Carolyn Jones as part of the Living Proof project. Don was asked before the shoot what kept him going. He thought of his mother, who is pictured wearing earrings Don had bought for her but had never seen her wear. Some of the other people Jones has photographed can be seen on the following pages. (For more on Living Proof, see page 31.)

Savage Grace

Two years after Bob passed on, I sat with Stephen and Ondrea Levine in a hotel room in New York City, talking about the plague. Stephen rolled a cigarette. Next to him sat his bewitching wife, whose unlikely recoveries from cancer and lupus could put the chaplain at Lourdes to shame. They spoke about how much Bob, and people like him, were changing. "The truth is that nowhere on the planet—not in any ashram, monastery, or school—is spiritual awakening happening more rapidly than in the AIDS community," said Stephen, lighting up. "Nowhere do you find this enormity of heart, the dying nursing the dying, lovers burying lovers. It's completely extraordinary."

His remark has remained with me like a credo through the years, as I—and thousands like me—continue to "die by inches." While it's true that our lives have been shattered by the HIV virus, it is also true that within this destruction, profound insights have occurred, which have lead to a deepening of vision, purpose, and faith. Knowing we may die very soon, we've been forced to look toward eternity; to come to treasure what we have; to realize, as a monk once wrote, that "if the cardinal's flight from bank to bank were less brief, it would also be less glorious."

In this intensified climate, growth often accelerates. With nothing left to lose, risk takes on new meaning. Changes that seemed daunting before an HIV diagnosis seem like nothing compared to the prospect of dying without having done them. With old values falling away, many of us have made what seem like erratic, extreme movements in search of happiness and spiritual meaning. One friend left his career as a Wall Street attorney to meditate and chop vegetables in a Zen monastery; another gave up a successful arts career to run grief support groups and to train to be a therapist. A drug addict got sober, then, finding out that she was HIV-positive, became a national spokesperson for women with the virus.

Among those who have not been infected but work closely with the community, these changes have been equally inspiring. A woman I interviewed left her home in the suburbs to nurse her son until his death from AIDS, then became ordained as an interfaith minister. A socialite and fashion designer abandoned her glittery life to fundraise for AIDS organizations, eventually opening her own nonprofit center in New York City. These personal revolutions, set in motion by tragedy, have heartened and reminded us that even in the worst of times, disaster can be used to draw us nearer together, to inspire us to become authentic, to open our hearts, and to seek enlightenment.

For me, the relationship between HIV and spiritual life has been equally fruitful and dramatic. It began on a trip to Jamaica in 1986. Having coffee with my best friend John in our hotel room, I discovered a purple spot on his foot that hadn't been there the day before. Five months later, panting behind an oxygen mask, John suffocated to death in a room overlooking an airshaft in Roosevelt Hospital. Knowing that my own funeral could be next, I panicked, not only for fear of dying, but also of realizing how ignorant I was in terms of my inner life. Quitting my vacuous career in publishing, I followed a mystical friend to Germany, where I met my spiritual teacher, Mother Meera, then continued on to India, where I took up the long-avoided challenge of writing fiction. Suddenly, everything was urgent, nothing could wait, and while this awareness of emergency created anxiety, it also brought my life into focus.

Even in the worst of times, disaster can be used to draw us nearer together, to inspire us to become authentic, to open our hearts, and to seek enlightenment.

Returning to Manhattan deeply changed but forced to earn a living, I forewent limousine chasing for the journalism of consciousness. Although I had long assumed I was HIV-positive, and acted accordingly, it was not until 1989 that I finally surrendered to my new lover's insistence on taking the blood test. I'll never forget the look of pity on the technician's face as he read my results. I assured him, in chronic caretaking fashion, that I was just fine. (I was more upset by my 24-year-old lover's positive test result than by my own.) But as the news sank in, I discovered that the transition from a shadow of doubt to confirmation was more significant than I'd anticipated: the leap, in essence, from dating to marriage. When this virus becomes a formal part of you, your identity shifts. In the same way that having a ring slipped on your finger serves to tie the knot, acknowledgment of HIV renders peaceful cohabitation with this strange bedfellow a necessary, everyday affair.

For me, this has been the ideal predicament: carrying a potentially fatal bug (with its urgent message not to waste time) while remaining outwardly unscathed. I've often said that AIDS has actually saved my life, propelling me to change, encouraging me to confront what's difficult, urging my fascination with things divine. There is nothing Pollyanna in this; it does not imply that I'd have chosen this virus, or that I would not cure it tomorrow if I could. But there have been undeniable benefits to having the myth of immortality exploded. Like thousands of others living in this limbo, I've found depths and doors and potentials *in extremis* that I didn't know existed before. Forced to look beyond the body for metaphysical meaning, I've learned that within the horror lies a tremendous mystery.

Still, it's hard to be grateful for suffering. My feelings about AIDS are more complex than gratitude can articulate. They exist in a realm beyond words, inspired by the awe at this fabulous pattern of death, grief, and regeneration, at watching yourself and others transcend terrors you thought would kill you. This intimacy with suffering puts you in a state like the one described by Hindu teacher and AIDS pioneer Ma Jaya Bhagavate of being in "complete agony and complete ecstasy" at the exact same moment.

Unfortunately, not everyone agrees about the honey in the rock. Due to my own transformative experience, and those that I've witnessed around me since the appearance of AIDS, I came to my research expecting others to agree with this perspective. I was wrong. In point of

fact, 13 years into an epidemic that is only getting worse, the "S" word (spirituality) has come to have a surprisingly checkered reputation in the AIDS community. Speaking with people with AIDS (PWAs) and their lovers, therapists, doctors, ministers, authors, and gurus, it often seemed repugnant to discuss God in the midst of affliction, rather like rhapsodizing on My Lai.

"It's hard to say anything good about AIDS," admits Karen Ziegler, a minister who works with the Metropolitan Community Church in Manhattan, "I just want it to be over." Instigating conversations about spirituality in the presence of suffering, I learned, is to risk vulgarity, to miss the point, to literalize what is by its nature subtle, personal, and silent. As Joe Miller, a PWA living in New York, puts it, "Spirituality is like sex: The ones who really have it don't talk about it."

There are two primary reasons for resistance to the "S" word. The first concerns the attitude of organized religion toward homosexuals, who continue to dominate the AIDS community. Paul Monette, whose memoir *Borrowed Time* (about nursing his lover until his death) put AIDS on the literary map and whose *Becoming a Man* won the 1992 National Book Award for nonfiction, makes no bones about this ambivalence. "Organized religion is the world's worst problem," says Monette, who has lived with AIDS since 1989. "Fundamentalism the world over is why we've been genocided as a people." Karen Ziegler agrees. "Although gays have always been a spiritual people, many refuse to use the word because they've been so abused by the church. The fight against homosexuality in organized religion is the biggest [battle] in the church since the days of slavery. People talk about salvation, but for many of us, coming out is like salvation. Our presence through AIDS is challenging people who wouldn't have come to terms with their homophobia in any other way. That's what I call spiritual growth." Even within the Catholic Church, whose stand on AIDS remains questionable (the gay group Dignity was recently refused communion in Los Angeles, then taken in by the Episco-

Ron Johnson **(right), the New York City Coordinator for AIDS Policy, has two great passions: laughter and cooking.**

palians), in-roads have begun to be made, with church-run hospices functioning in San Francisco and other urban areas.

Still, the sheer magnitude of AIDS and all the attendant issues is enough to turn some former believers into skeptics. John McIlveen, who heads the volunteer division of the PWA Coalition in New York, is one of them. "My faith has dwindled during the AIDS crisis," admits this former Catholic. "It's left me more existential." A blue-eyed all-American of 33, McIlveen has not been infected but lives with an HIV-positive lover. The shadow of death weighs heavily. "The serial loss is devastating. I've watched at least a dozen volunteers die in the past two years. I ask myself, if there's a God, why is this happening? This whole tragedy has made me cynical."

This cynicism has only been strengthened by certain factions of the new age movement, whose saccharine philosophy is the second major obstacle to spirit among individuals groping with the gritty reality of AIDS. Responding to cries of helplessness and fatality following the first diagnoses in the early 1980s, the psychological pendulum swung to the opposite extreme in an effort to rally people away from victimhood toward the possibilities of self-healing and survival. Foremost among this group of advocates was Louise Hay, a Science of Mind minister whose books (including *You Can Heal Your Own Life*) have sold in the millions and whose name has become synonymous with pop notions of self-created reality and "taking responsibility" for illness.

Beginning in 1985, Hay (who refused to be interviewed for this piece) formed the first of many AIDS healing circles across the country, urging the six men in her living room to drop their self-pity and take charge, using affirmations, visualizations, mirror work, teddy bears, and other devices aimed at fostering self-love and its supposed correlate, spontaneous physical healing. Proffering what Paul Monette dubs "Readers Digest psychology," with its simplistic think-happy-get-healthy message, Hay seemed to offer a sunny alternative to a slow and painful death. Those at risk, and those already dying, flocked to self-empowerment's ray of hope, following the injunction to uproot their evil death wish by becoming vigilantes of negativism.

This philosophy's dangerous fallout has struck many, including me. Working as a volunteer at New York's Cabrini Hospice, I was spoon-feeding a very sick patient one day when a member of the New York Healing Circle came by for a visit. "I always knew he was a negative person," this fellow said to me afterward in the hall, referring to the man in bed. Asked why I was wearing a mask in the room, I informed him that our patient had active TB. He laughed at my self-protective precaution. "But no one can give you anything you don't want!" he scoffed.

AIDS has actually saved my life, propelling me to change, encouraging me to confront what's difficult, urging my fascination with things divine.

Years later, in a more sophisticated fashion, Marianne Williamson gained enormous popularity using a channeled Christian text called *A Course in Miracles* to promulgate a similar outwit-the-darkness thesis, leading many, through misinterpretation and oversimplification, into a philosophical quagmire of obfuscation. Though nominally nonjudgmental, the *Course*, like Hay's Science of Mind, may set the seeker up for a fall with its fierce emphasis on positive thinking. "There's this underlying sense of right and wrong," says Cynthia O'Neal, a prominent spokesperson for the AIDS community who helped Williamson found the Manhattan Center for Living. "There's an enormous difference between being responsible for your illness and being responsible to it, doing everything in your power to help yourself heal and so on. With the former, self-blame is almost inevitable," claims O'Neal, who left the fold two years ago to form her own nonprofit center, Friends in Deed.

"It's all a little too flip," says Eric Schneider, a gestalt therapist and martial arts instructor who works with a largely HIV-affected clientele in New York City. "I spend a lot of time with people deconstructing ideas from Louise and Marianne. Without guidance, you can go very far down a wrong path."

These failures can't be pinned solely on these new age messengers, however. "It wasn't entirely their fault," admits Sally Fisher, a former acting coach who founded the AIDS Mastery workshop seven years ago. "In the beginning, there was a misunderstanding about the parthenogenesis of the disease. People thought they were keeping AIDS away with affirmations, but actually it was just what we now refer to as the 'honeymoon period.'"

Having already nursed a son through adolescent Hodgkin's disease, Fisher was no stranger to hospital rooms when theater friends, diagnosed with AIDS, urged her to "get off her ass and do something useful." Adapting her performance skills to the need for expression and truth-telling incumbent on people facing death, Fisher soon discovered that her own nuts-and-bolts behavioral approach to healing was at odds with the idealistic spoutings of others. "The new age became another kind of fundamentalism, a storehouse of magical thinking for people in search of a magic bullet. Unfortunately, when they finally did get sick, they blamed themselves for doing something wrong."

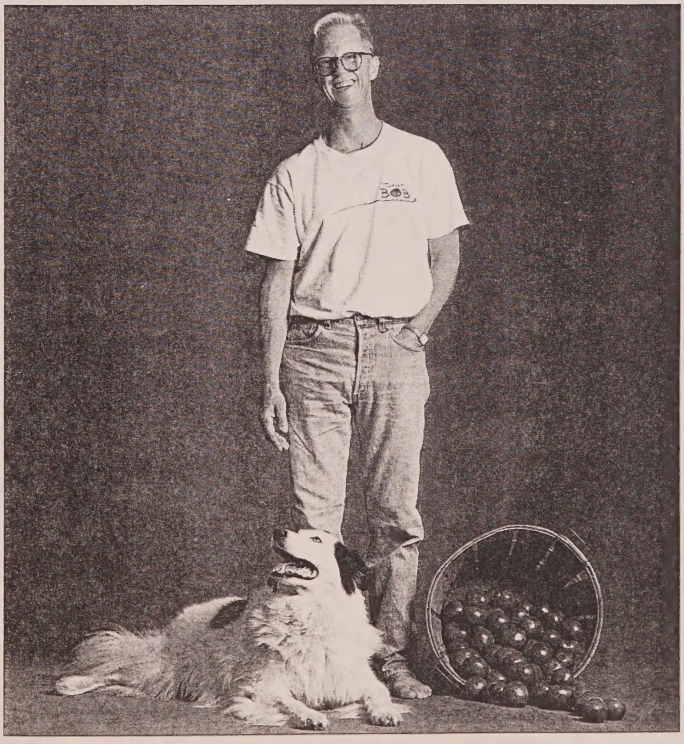
Thus many infected and dying individuals, alienated by both the religious and new age contingents, found themselves in no man's land, compelled to create an approach to healing and spirituality forged from their own experience, meeting their own particular needs, incorporating their own unique gifts, and drawing from the best of mainstream and alternative sources. "There are a million possibilities between death and denial," says Sally Fisher. "We just had to find them."

Moving into this realm of possibility, the first thing that becomes obvious is the crucial role that solidarity, revolt, and imagination have played in the AIDS movement. Hitting a marginalized population "already high in survival skills" (according to Schneider) and eager for their civil rights, the epidemic has acted as a social powderkeg, unleashing astounding powers of resourcefulness and community support, an alembic in

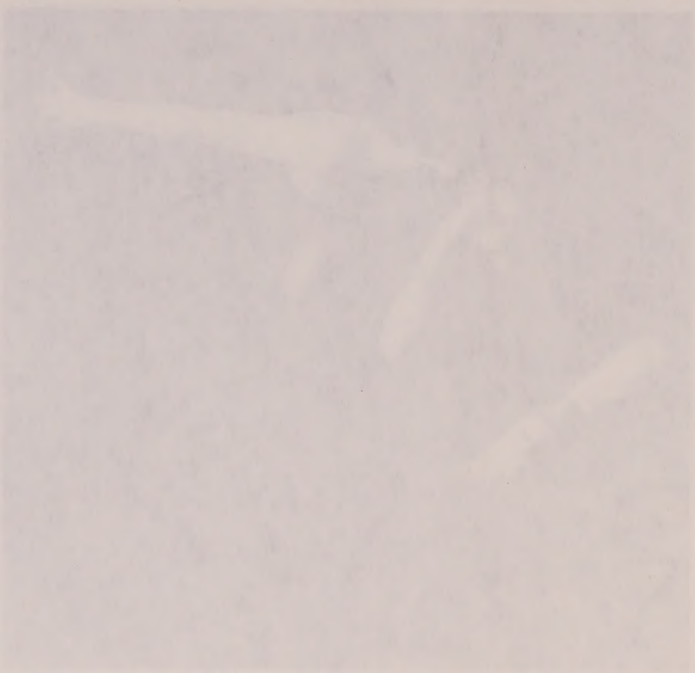
which activism and spirituality are distilled and linked.

Witness the facts. In 1983, two years after the first cases of Gay Related Immune Deficiency (GRID) were diagnosed, 45 community-based organizations had formed around the country. By 1990, this network had snowballed to nearly 800 groups (with services including legal aid; alternative health care; political advocacy; and every manner of medical, psychological, and pastoral support), organized to meet the needs of people affected by HIV and the individuals around them. This explosion of *caritas* has been fueled by desperation and the growing realization that, as outsiders in a right-wing era, this community would have to care for itself or suffer even more deeply. According to sociologist Susan Chambre, volunteers offered their services in droves as a "way to cope with the uncertainties and ambiguities of the epidemic, as well as a way to bear witness" to this unexpected tragedy. Among these groups, many, such as New York's PWA Coalition (where 75 percent of the volunteers are living with AIDS) were instigated by people with AIDS themselves. "Again and again, we've seen the dying cross the wound to help their brothers," observes Stephen Levine. "First you're outcast by society and then you're told you might die!" adds Sally Fisher. "This group, which had been legislated against and vilified, had to find a way to nourish itself in the face of disaster."

Anger has been one tool that, when used skillfully, has accelerated self-actualization as well as shifted the balance in social power. Many have turned to civil disobedience to protest medical, political, and legal injustices and have found it to be a vehicle for both empowerment and the release of hostility bred from oppression. "Social consciousness is crucial to everyone in a beleaguered world," Paul Monette told me in February, en route to deliver a scathing speech before the Library of Congress in Washington. "By



Above, *Gordon Rogers* and his friend Victoria, who is wearing a dress he sewed for her. Below, *Tomato Bob* and his friend Bill. Bob has a vegetable stand and a number to call for information on the weekly arrivals of new produce.



taking anger away from people, some forms of spirituality keep people from becoming part of the political battle. Anger against injustice is the most significant emotion an adult can feel."

Inspiring as anger may be, however, it is only one piece of the healing puzzle. "It may help change laws, but if it helps their lovers dying in bed, I don't know," says Stephen Levine. "There's a need to find something to sustain yourself in the face of death that goes deeper than rage," says Fisher.

Determined to be active martyrs instead of helpless victims, many PWAs are working hard to locate this middle path between rage and compassion. Their drive to transform personal suffering into public good is mythic in texture. According to Paul Bellman, a Manhattan internist whose practice is largely devoted to people living with HIV, "People with AIDS are the real heros of our time, even more than those suffering from other diseases. Being young, many people with HIV embark on a kind of medical, psychological, and spiritual quest to find better treatments and discover themselves. It becomes a hero's journey."

Ten years ago, Dean Rolston was a high-powered Wall Street attorney, art world maven, and part-time Zen student, up to his eyebrows in New York City hysteria and longing for a break. An urbane man of 40, renowned on two coasts for his remarkable wit and trademark headscarf, Rolston grew tired of elbowing the best and brightest, and used AIDS as an exit from a world he'd outgrown. "This illness gave me permission to change," emphasizes Rolston, who ditched Manhattan for the serenity of the Green Gulch monastery outside of San Francisco following his diagnosis in 1987.

This change of scenery has had unexpected rewards, both spiritual and medical. Like an increasing number of PWAs, Rolston has continued to outlive his physicians' prognoses for survival (It's almost embarrassing," he laughs), attributing his continued relatively good health to changes of life-style and priorities.

Living with AIDS, he claims, has radically transformed his character. "You become more tender and expressive as you pierce the veil of ordinary reality and seek deeper things," says Rolston, who now channels his professional savvy into writing (HarperSanFrancisco is planning to publish his AIDS memoir in 1994), and curating art shows for charitable organizations, such as the San Francisco Zen Hospice. Often this tenderness leads to unexpected spiritual insights. During a recent brush with death, Rolston reports an experience of *satori* (enlightenment) that took him to "a completely different level of reality, a buoyancy lighter than air." "You begin to realize that everything is perfect around you, pleasant and unpleasant," he explains with a characteristic mix of amusement and dispassion. "Even the things you dread become fascinating."

Many people with HIV embark on a medical, psychological, and spiritual quest to find better treatments and discover themselves. It becomes a hero's journey.

In this heightened state, the sacredness of everyday life often becomes more vivid. "The truth is, there are Buddhas everywhere!" Rolston laughs. "It's astonishing where you run into them—in the glowing eyes of a boy on the bus, in the Cockney nurse sticking needles in your arm." What's more, it doesn't necessarily take sitting on a zafu to realize this. "Dying is very intense spiritual practice, if you're paying attention," notes Rolston. "Formal practice begins to seem redundant." For other people with AIDS, the inverse holds true. According to Dr. Rick Levine, a number of patients at the Maitri Hospice, with no meditation background, have taken up rigorous practice and been ordained as Buddhist monks in their last months of life.

Although the experience of deepened spirituality seems to be nearly universal among those touched by AIDS, many who call themselves atheists prefer to clothe their epiphanies in humanist terms. "My faith is in those I love and trust," says John McIlveen, who finds inspiration in "the charity of other people." Paul Monette, an ex-Episcopalian who continues to take communion, feels similarly, citing the "exquisite examples of people living out their love" as God enough.

This feeling of brotherhood is the spiritual bridge for many who are put off by religious language. Moved by a sense of kinship with, and responsibility toward, those who have died before him, *New York Times* deputy editor Jeffrey Schmalz was the first reporter to come out in print about his disease. He has used his situation to increase sorely needed, sensitive AIDS coverage in the mainstream media, and has even raised the issue of spirituality concerning the epidemic. In an editorial last year, Schmalz described a sudden urge to go to church before having surgery on an irreversible brain condition. Claiming that it would be "hypocritical to turn to God in a moment of desperation," Schmalz was amazed by the flood of letters (and Bibles) that arrived after the article appeared. "People wrote to say that crisis is exactly when one should turn to God," Schmalz tells me in the newsroom. "This is not to say that when my time comes, I won't be a hypocrite. There's an old saying that there are no atheists in foxholes," he says with a smile.

While holding to his skepticism, Schmalz sees that mortal illness cannot help but instigate existential questions. "AIDS has forced me to rethink all this rather dramatically, which is a spiritual happening in itself." In the meantime, his inspiration comes from the dead, whose cause he continues to champion. "As the end approaches, my friends who've gone seem very close," says Schmalz. "They're my conscience and my cheering section, urging me on, giving me strength. When I get very tired, they say to me, 'Not yet, Jeff, keep going.' "

While it would appear that such inspiration is a welcome addition to character, referring to AIDS as a benefit causes a knee-jerk reaction in almost everyone. "When people say that HIV's a gift, it takes for granted all the other gifts we're given every moment. That pisses me off!" says Eric Schneider. Even the faithful find themselves bemused. "I'll tell you, honey, this disease is a blessing I could live without!" says Phyllis Marks, stroking the head of her Maltese side-

kick, Susie. A sexy woman of 50 dressed in skin-tight jeans and cowboy boots, Marks has known she is HIV-positive since 1986. Though ironic about this equivocal gift, she admits that the wake-up call came just in time. "I needed an excuse to turn things around," claims Marks, echoing Dean Rolston. "I'd been searching all my life through drugs. Even though the process started with my getting sober, AIDS is what finally brought me to my knees."

"I can vouch for that," says her lover, Leila Gastil. Following Phyllis's diagnosis with AIDS-related lymphoma in 1991, the couple began a year-long practice of heart meditation with a Tibetan monk in New York. "In crisis, your powerlessness forces you constantly to turn to God," says Gastil. "For me, that has become the most comfortable place to live, with or without the disease. This community understands and supports that."

This support offers tangible results. "When you have AIDS, the concepts of home and family become crucial," admits Marks, who has called on the community in darkest times. "Whenever I've had a major treatment—spinal taps, bone marrow transplants, chemotherapy—I've asked people to pray for me. The amazing thing is that I never experienced any pain whatsoever when there was unified prayer. Knowing that people were sending me their love took the pain away." "That was an extraordinary spiritual lesson," concludes Marks whose cancer is now in remission.

Behind the army of individuals with AIDS is a sizable reserve of equally devoted but uninfected helpers, religious and secular, who have taken on the full-time job of helping people with AIDS bear their burden. Far from being martyrs, those that serve know that they're receiving as much as they give through the formidable opportunities for compassion that AIDS presents.

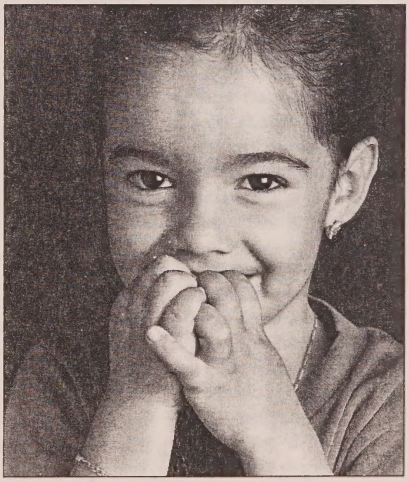
"It's an incredible privilege to be invited to share a person's death," says Ma Jaya Bhagavate, whose remarkable work in this community has distinguished her among American religious figures since the beginning of the epidemic. In addition to founding a score of charitable organizations around the country, Ma Jaya regularly visits hospitals and children's homes in Florida where her ashram is located, and around the country. Born in Brooklyn, this Hindu teacher is loved for a gutsy, flamboyant style that calls everyone into the fray. "Whoever falls into my arms, I hold," says Ma Jaya in her Coney Island accent. "I juice them up so they don't die dry. If spiritual teachers would get into the trenches and kiss these people's brows and lesions, they'd see that you don't have to preach about God. You just gotta be ready with a God answer."

Ma Jaya counsels devotees with AIDS to keep on giving till they drop. "You think I let my gay men die in peace?" she says. "Hell no. They work their butts off." In the process, she reminds them always of the blessing of service. "You gotta remember that when you're witnessing somebody's death, you're a guest," she insists. "That honor must be respected."

Cynthia O'Neal understands this privilege well. Married and the mother of two grown sons, O'Neal was already on a spiritual path when her colleagues in show business began coming down with AIDS. Looking for ways to cope with her grief, this graceful ex-model found her way to a Louise Hay workshop, and there had an experience that changed her philosophical and professional life.

"There was a young man asleep on the floor next to me," she remembers, as we sit on a sofa at Friends in Deed, the plush, lower-Manhattan center O'Neal founded with Oscar-winning director Mike Nichols. "He was pale and thin, obviously ill, and without knowing why, I suddenly picked him up and put him in my lap. He opened his eyes, smiled, and went back to sleep. Later, Archie—that was his name—told the group that the hardest thing about having AIDS was the fear of letting everybody down. At the break I told him that I'd love to be his friend and that if he needed to die, it would be fine with me.

"Archie lived another year; then one day he elected to stop all treatment. His body was worn out, but spiritually he was



Above, *Vilma Santiago*, grandmother of seven. Center, *Veronica*, who, along with her mother, is HIV positive. Below, *Phyllis Marks* (at right) and her lover, Leila Gastil.

just fine. The night he passed away, Archie, his lover, and I were all hugging on the bed. The room was candlelit; chamber music was playing. It was so exquisite, like a birth. This experience completely allayed my own fears about dying. Archie taught me how to die."

Lyrical as this sounds, O'Neal admits that not everyone is so lucky. "People die the way they lived," she says. Recognizing this, therapists such as Eric Schneider use their practice to focus as much on the psychological and spiritual surrounding HIV as on the virus itself. "The thrust of my work is that—since none of us are getting out of this alive—HIV doesn't matter much," says Schneider, sucking on a pipe in his Chelsea office. "At root, these aren't AIDS experiences, they're human experiences." But working with individuals whose life expectancy may be curtailed alters the intensity of the therapeutic process. "In terms of self-actualization, many people with this disease are on the fast track, which makes me speed up the work." This sense of urgency creates commensurate opportunity. "If I'm teaching aikido, and push someone beyond his limits, he will tap into a deeper resource. Emergency causes us to access something that transcends the usual ways we organize our lives."

Many of us living with HIV and AIDS are making concerted efforts to integrate psychospiritual healing with the physical realities of immune deficiency. Called upon to reimagine a condition deemed incurable by the mainstream medical establishment (but, in the light of growing numbers of long-term survivors, perhaps not so), we rely upon physicians (as well as therapists) who are willing to support us in our struggle to cultivate hope during this twilight period of pessimism and uncertainty.

"Most people living with HIV are relatively healthy," notes Dr. Bellman, adding that he believes AIDS will ultimately be shown to be a "curable disease." Alan Pressman, a veteran chiropractor and longtime advocate of alternative approaches to healing AIDS, agrees. "While accepting the biological component as an absolute necessity, people with HIV are going far beyond that, more than any group I've ever seen," says Pressman. "Nearly 100 percent of my clients are involved in more than just a biological approach to their illness." "We need to encourage the patient's search throughout this process," Bellman adds, "to look at it creatively and to support both body and soul in the healing journey."

One emotional aspect to consider has to do with feeling the sobering powers of grief. "Grief drives us to seek understanding and unity," explains Stephen Levine. "There may be nothing beautiful in suffering, but in the opening to pain something profound can come about. Unfortunately, brokenhearted America doesn't know how to grieve. Temples should be built for this purpose alone, sanctuaries for loss and weeping. The truth is that in 1993, in a world of such indifference and hostility, we don't need some fancy spirituality. If we could touch our pain with mercy, this would be Eden."

Changes that seemed daunting before an HIV diagnosis seem like nothing compared to the prospect of dying without having done them.

Ma Jaya emphatically agrees. "People have forgotten that death has a heart," she says. "You just gotta stop and listen."

Yesterday I went for my three-month checkup. On route, I picked up *The New York Times* and saw a picture of the Pope blessing a child with AIDS in Uganda. The caption noted that despite the fact that Uganda has the highest number of AIDS cases in Africa (over a million infected in this half-Catholic country), the Vatican continues to claim "chastity as the only defense" against the spread of HIV.

At the clinic, my doctor looks happy. He approves of my latest lab results; he is pleased by the numbers and ratios. My T-cells, whatever those are, seem to be normal. I'm not in immediate danger.

I leave the office feeling smug, not quite grateful enough (it seems to me) for continued good health as my friends get sicker. At home, an invitation has arrived, announcing the baptism of my best friend Carole's granddaughter. Carole, whose rosary hangs by my desk, was an ardent Catholic who died of AIDS last year after being infected during the only one-night stand of her life. Here was the granddaughter (named for her) she dreamt about but didn't live to see. I R.S.V.P. in her stead.

In an ironic passage, Aristotle defined luck as the moment the arrow hits the guy next to you. This is cold comfort, as the "worried well" and anyone dealing with survivors' guilt can testify. There are even, they tell us, a faction of seronegative extremists who want to have AIDS but don't. I've never been that crazy (my train will take off soon enough), but I do admit to feeling resigned sometimes: surreal, split off, already dead. So many have already left the station; death is no longer a surprise. Sometimes it doesn't even hurt.

Once a father approached a Buddhist master and asked how he could possibly bear to live in a world where he could not protect his children from annihilation. The master picked up a crystal goblet. "I like this glass," he said. "It makes a lovely sound when you flick it, and everything tastes more delicious when poured from its delicate shape. But when a wind comes along and shatters it into a thousand pieces, I won't be surprised. You see, I know the glass is already broken."

Is this spirituality? Perhaps. Writing this story, I came to question the implications of that word more than I had. It seems to imply some separateness, some privilege, some otherness that may not be useful. Is it spiritual, or simply wise, to admit you're already broken? Thanks to HIV, I have come to live with this fact completely. Every morning the routine's the same. I open my eyes, check my armpits for lumps, the sheets for

perspiration. I search my body in the shower for purple lesions, then inspect my tongue in the mirror for signs of thrush. At first these rituals were disturbing. Now they simply keep me on my toes.

The funniest thing about it is that I've grown to love this way of life—the intensity, clarity, poignancy—the ability to see things at their value, to measure life, at last, by its true and terminal standard. I laugh louder these days and cry at nothing. I work until my fingers are sore and I exercise my heart. I envision the future with a jaundiced eye and think almost nothing about the past.

Of course, AIDS is terrible—a sentence to the guillotine. But terror can enlighten. Affliction has its gifts. Rainer Maria Rilke, who refused medication during his excruciating final illness, described this in a letter to a patroness. "It is true," wrote the poet, "that these mysteries are dreadful, and people have always drawn away from them. But where can we find anything sweet and glorious that would never wear this mask of the dreadful? Whoever does not, sometime or other, give his full and joyous consent to the dreadfulness of life, can never take possession of the unutterable abundance and power of our existence; can only walk on its edge, and one day, when the judgement is given, will have been neither alive nor dead."

This bitter wisdom cuts to the bone and reminds me of visiting an Italian artist years ago in his studio. He was in the process of restoring a neglected painting from the days of Michelangelo. Fascinated, I watched him dip a brush in a tin of stinking, acidic solution, then slide it across the encrusted canvas. Magically, an eye appeared through the grime, then the face of a smiling Madonna. Soon, the full pieta shone through, bathed in acrid-smelling tonic.

Our veils need dissolving too, else we miss the picture. Without a burn, a taste of death, we are strangers to the mystery. Shrouded by fear, we are blind to the fact that God makes seeds out of rolling heads.

Mark Matousek is a contributing editor of *Common Boundary*. His last article, "Addicted to Sex," appeared in the March/April issue.

Living Proof

"AIDS is not a pretty way to die because there's shame attached to it."

"Death is very real to me . . . the sense of being a stranger inside my own body is a result of that intensity, that increased sense of mortality."

"This sense of poison being just inside my skin made me feel very unattractive."

These quotes are from people with AIDS or HIV and were taken from the recently published book *Muses from Chaos and Ash: AIDS, Artists, and Art*. They depict the personal tragedy of AIDS and reflect popular impressions of the disease as a debilitating, gruesome illness that steals life from the body as it crushes the spirit. The media have done little to discourage this imagery; plague metaphors still often accompany stories on AIDS, and the language of decay is still the norm in newspapers and on television.

George DeSipio and parents

Carolyn Jones is well aware that negative perceptions surround AIDS, often making its victims feel like pariahs. The 35-year-old New York photographer was contacted in early 1992 by her friend Michael Liberatore when Liberatore's companion, fashion executive George DeSipio, landed in the hospital after contracting AIDS-related pneumonia. During his stay DeSipio was stunned by the death-march tone of most AIDS media coverage, and he and Liberatore asked Jones if she would take more positive portraits of people with AIDS and HIV. Jones jumped at the chance.

The result is Living Proof, an acclaimed, upbeat collection of 50 black-and-white photographs of people living with HIV and AIDS that premiered in New York City on World AIDS Day (December 1st) last year, and will travel to other cities in the future. One of the shots appears on this issue's cover, and others illustrate Mark Matousek's article on AIDS.

"What we're looking for is the next thing that's happening with AIDS," Jones says. "First people had to learn that AIDS ends an awful lot of lives. But now it seems as though there are a lot of people living with AIDS. I've met and photographed people who have been HIV positive for at least 10 years."

Indeed, the people in Jones's pictures aren't just living—they are laughing, swimming, and cooking, among other things. Some are pictured with family, friends, or lovers. One shows a cleancut Boy Scout in full uniform, another a grandmother in hot pants and roller skates. The pictures are realistic and touching without patronizing their subjects. Without denying the terrible realities of the disease, Jones humanizes those suffering from it.

"Nobody working on this project is trying to put a happy face on AIDS, or on death," Jones says. "That would be an absurd thing to do. What we are trying to do is provide hope for people who are living with this disease and show them that you can live a productive life and it can be happy and you can look great. It's not an immediate death sentence. Some of the people that I've met just need a little bit of hope to push them to the other side of it—to say, 'Yes, I can live with it.' "

Many people diagnosed with AIDS and HIV are doing just that. "Even though I was acutely aware of being potentially face-to-face with death," a film maker diagnosed with HIV says in *Muses from Chaos and Ash*, "I didn't feel like I was dying. I felt that finally I knew what it was to live, to really call forth all that is in you and demand the highest of yourself, the noblest and truest, and to offer that as a gift to yourself as well as to others."

—Mark Gauvreau Judge

For more information, contact Carolyn Jones or Georgia Goodrow at Living Proof, 167 Spring Street, New York, NY 10012, or call (212) 431-9696.

EDITORIAL

AIDS and Social Work: A Decade Later

IN THE BEGINNING

It has been ten years, since a student named Diego Lopez asked if I might serve as a consultant to him in his work with gay men who had been diagnosed with Kaposi's sarcoma, a rare cancer caused by the collapse of the bodily immune system. Diego was approached by a group of gay men who were alarmed at the sudden occurrences of illness among their companions and friends. In 1981 these men reached out to each other for emotional support and sought to win recognition of a disease, in order that research funding could commence. During the following year they incorporated the Gay Men's Health Crisis (GMHC), the first volunteer organization to address the multi-dimensional character of what was then an epidemic of a few hundred persons, largely identified in New York City, San Francisco, and Los Angeles.

The sense of alarm sounded by these early gay leaders of the

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fledgling AIDS movement met with resounding apathy, if not antagonism, so ably documented in the literature (Shilts, 1987; Greenly, 1986; Kramer, 1989). Historical and literary analyses (Camus, 1952; Mann, 1954) give abundant evidence of how the portent of plague is denied with both simple and elaborate defensive strategies that are slowly deconstructed by the mounting death count, the widening experience of personal tragedy, and finally the discrediting of public officials' avowals. In our post-modern period, such avowals occur in 30 second bites of television time that mediate the reality by which AIDS and the Human Immunodeficiency Virus (HIV) are described as the problems of people who are prone to moral lapses and aesthetically distasteful sexual and drug abuse behaviors. By the start of the next millennium, the worldwide epidemiological projection of the toll of infection, illness, and death (Altman, 1991) is estimated to reach 40 million people.

The role of the social work profession in addressing the AIDS pandemic has not received the recognition it deserves, not only in establishing HIV/AIDS services, but in creating the very definition of AIDS as a biopsychosocial phenomenon that goes beyond an entrenched, narrow bio-medical perspective. In a paper delivered November, 1983 in Washington, D.C. at the Professional Symposium of the National Association of Social Workers, Lopez and Getzel (1984) noted:

> The occurrence of acquired immunodeficiency syndrome (AIDS) in gay men, intravenous drug users, and others has engendered widespread anxiety in the public mind, diverting attention from the enormous problems AIDS patients face in their daily lives. Gay and other populations who have been labeled potential victims of AIDS are subjected to social ostracism and direct abuse of their rights as citizens . . . The victim's fate may be reckoned as a type of intractable evil from within or as the result of the individual's failure to ward off noxious agents by an act of will. On occasion, the victim may be viewed as a symbol of the human collectivity's sins or shortcomings. Such explanations, however, only comfort for a short period of time when contagion is growing and number of ill increases. (pp. 387-388)

Who is Rock Hudson, who is Liberace, who is Halston and who is "Magic" Johnson? Is it the death toll or who is dying, that will cause the citizenry of this nation and the world to face up to their biopsychosocial vulnerability to HIV and AIDS? HIV and its effects are integral parts of our lives now, and in the future, short of vaccines and miracle cures.

The pernicious effects of denial on psychological and cultural levels present extraordinary challenges to social workers in their daily practice with people and in their introspection about personal and public involvement in the AIDS pandemic. Tavares and Lopez (1984) wrote that the gay community should be justifiably proud of their pioneer establishment of AIDS organizations in New York City, Los Angeles, San Francisco, Houston, Atlanta and throughout the United States. These organizations opened up communications between different levels of government and affected communities. Since the first recognition of the pandemic, AIDS has taught professionals and lay volunteers about the interdependence of affected groups for their common survival. Each segment of society feels the consequences of illness and mortality.

The rapidity of the development of HIV prevention efforts and AIDS directed social services is in large measures due to the tenacity of social workers in the community and hospital-based settings. Mel Rosen, GMHC's first executive director, and Diego Lopez, GMHC's initiator of crisis intervention services, stimulated and shaped the direction of community-based services throughout North America, Europe, and the rest of the world. Grace Christ, Lori Weiner, and Rosemary Moynihan (1986) outlined the roles that social workers would assume in the treatment of the psychosocial consequences of AIDS. Larry Caputo (1985) and Luis Palacios-Jimenez sounded the alarm about the AIDS pandemic as it affected a growing population of ill intravenous drug users and their family members. Social workers George Sonsel and Sally Jue (1987) at the Los Angeles AIDS Project, Caitlin Ryan (1987) at AIDS Atlanta and Whitman-Walker Clinic at Washington, D.C. and Judith Macks (1987) of the San Francisco AIDS Health Foundation were among the leading figures in conceptualizing the role of social work during the emergence of the pandemic.

Models of hospital-based AIDS services, particularly for families

in inner city neighborhoods, were conceptualized by Esther Chachkes (1987) with collaborative research on fetal and household transmission done by a team of social workers consisting of Monnie Callan and Lauren Gordon with Dr. Gerald Friedland (1988), an infectious disease physician-researcher at Montefiore Medical Center in the Bronx, New York.

Luis Palacios-Jimenez and Michael Shernoff (1987) devised innovative methods to teach safer sex techniques through a group approach for gay and bi-sexual men. Aspects of their approach have been adapted for women and other groups. Shernoff (1988) has been a strong advocate for the inclusion of AIDS prevention as a significant aspect of clinical social work practice.

THE FUTURE

It with great pleasure that this tired and personally bereaved veteran of the social work profession's engagement of the AIDS pandemic had read the articles that follow, if only to see that social workers have not become inured to the complexity and tragedy of the pandemic. These articles add to knowledge and practice descriptions, and oddly enough complement one another by focusing on some of the central emphases that social workers must consider as they enter the second decade of effort and struggle.

The closing decade of the millennium has brought to our attention the changing character of the pandemic and its monumental social, economic, and political ramifications. Firstly, AIDS has changed the notion of how to deliver care; and it has set in motion a reconsideration of how case management must respond to young persons affected and their families. Secondly, the incredibly complex service requirements of families of color in the inner-city has become a prominent feature in social work planning and program development. For example, as many as 20,000 New York youngsters will become orphaned because of AIDS-related deaths of parents, and will need placement through child welfare agencies (Teltsh, 1991). And finally, the enormity of these other AIDS-related problems will challenge our societal and human predilection for denial.

DISCUSSION

Roberts and Associates' article provides a useful analysis of the multiple roles enmeshed in the case management of people with AIDS (PWAs) and the clinical issues arising from the biopsychosocial consequences of the HIV/AIDS. The case illustration of David and the complex problem-solving entailed in providing appropriate and humane health services is quite typical of PWAs' longer term survival, characterized by the likelihood of profound disease and HIV dementia. The question routinely becomes *who* plans: the client, the family, or the workers when disorientation and poor judgement is developing. Appropriately, much emphasis to date has been placed on maintaining the self-determination and the dignity of PWAs who have been routinely stigmatized because of their sexual and/or drug use histories. A professional's agony about how to proceed with a demented PWA should be an invitation to a collegial examination of ethical decision-making. Rejecting kin, the absence of available friends and neighbors, and frequent obstacles to the receipt of entitlements narrow options and the sources of guidance for social workers in their decision-making as to what is in the best interests of PWAs.

If PWAs benefit from medical treatment with consequent increased in their longevity, options for long-term home care and, in some cases, nursing home placement must be readily available. Unfortunately, we have little experience of how this can be effectively accomplished. Existing universalistic federal entitlement programs providing income or health care (Disability and Medicare insurances) have not significantly responded to the rapidity and severity of illness and incapacitation of PWAs and people with severe HIV symptoms.

In the best of resource situations, social workers serving PWAs and their families still must come to terms with numerous overwhelming emotional reactions of PWAs who face disabling, disfiguring, and disorienting illnesses and societal ostracism. The notion

that social workers can readily "work through" their emotional reactions to so many young people in crisis who are meeting premature deaths, must be questioned. Social workers doing AIDS work require careful and continuing rewards, respite, and support. Practitioners must be ready to explore their natural proclivities towards immersion, disassociation, and martyrdom which develop as less than positive survival strategies to cope with the distress, the rage, and pain of PWAs and their families.

Jimenez and Jimenez's article represents an important recognition of the need to establish culturally sensitive and specific service approaches for Latino families affected by HIV/AIDS. Heavy use of intravenous drugs, heterosexual and fetal transmission, and the lack of recognition of bisexual and homosexual behaviors are responsible for the disproportionate number of infected and sick people with HIV in Latino communities. The plight of Latino PWAs and their families is made difficult by widespread ignorance about transmission and the lack of entitlements to medical and income programs.

Jimenez and Jimenez are correct: formal provision of income and health care do not provide the guarantee that Latinos will receive necessary prevention and AIDS psychosocial services. Informal mediating structures that are culturally acceptable and effective must be used to make certain that more formal provision is accepted and used. Model programs that employ family support volunteers and home care services may represent a far more acceptable mode of service delivery to Latino PWAs. The need for bilingual and bicultural social workers and other providers calls for continuous reiteration, if effective services are to be offered people of color and of linguistic diversity. An essential aspect of service to the Latino community is an understanding of extended family networks, the role of churches, and other indigenous community organizations. This must be a long-term effort. Such human resource development in communities of color should be of the highest priority.

Rosenberger and Wineburgh's article represents more than a sophisticated clinical analysis of the utility and pervasiveness of denial among persons in social work treatment or psychotherapy, but a reminder of the difficulty that underlies all HIV prevention

activities, and the acceptance of a subsequent AIDS diagnosis. Denial, the most primitive of defense mechanisms with related defenses, are integrally connected to coping and adaptative strategies used to handle the specter of HIV infection and AIDS. Rosenberger and Wineburgh demonstrate through rich case examples that the psychogenic source of this denial is based on historic failures and confusions related to intimacy and the emergence of anxiety that makes the prospect of annihilation through AIDS unconsciously acceptable.

Only through the process of a corrective therapeutic experience with the worker and related insight work into historical conflicts, can clients understand the obstacles to their practicing safer sex. Accurate knowledge about HIV transmission itself is not a sufficient basis for practicing safer sex, if the underlying conflicts about intimacy and sources of annihilation anxiety are not understood. The social worker's stake in clients' efforts at safer sex gives reenforcement to positive and acceptable life sustaining behaviors.

If Rosenberger and Wineburgh's theoretical perspective has explanatory power, it gives some guidance to public health planners. Cognitive approaches to safer sex education should be employed carefully, particularly if they focus on the dire consequences of unsafe sex practices, thus stimulating annihilation anxiety and creating a paradoxical outcome.

The pernicious effects of denial are persuasively depicted, and suggest to me the necessity of constant reiteration of safer sex behaviors in new and culturally relevant ways–through mass media and through small group approaches–that have immediacy and saliency to different populations, particularly adolescents and sexually active adults.

Social workers must be more direct in exploring sexual histories with special attention to sexually transmitted diseases. Nothing can be more gratifying than to work with clients who remain HIV negative. When it comes to facing up to the risk of HIV infection, denial must be seen as reciprocally "contagious" between workers and clients as a response to death anxiety. Stimulating and continuous staff development on HIV prevention must be conducted in a planful fashion until the pandemic ends.

CONCLUSION

Let us thank these authors for these articles regardless of the pain incurred in reading them. During this pandemic social workers need a strong dose of collegial support and stark reality. Just as the difficulties in working with PWAs are enormous, the rewards are great (Getzel, 1991a; 1991b). In our effort to help, we may also learn a few lessons on how to face our own mortality. In any event, there is "no exit" from the pandemic. Let us get our professional act together and continue a noble tradition of service to those people others choose to forget.

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Obstacles to Effective Case Management with AIDS Patients: The Clinician's Perspective

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ABSTRACT. A social work clinician filled the role of case manager with multiple functions of discharge planner, client advocate, counsellor and educator in her work with a young male AIDS patient and his family. Material from this case is used to illustrate seven problem areas identified as obstacles to effective case management: (1) The stigma of AIDS and homosexuality (2) Lack of adequate family support (3) Impact of AIDS dementia (4) Ethical dilemmas in discharge planning (5) Conflicts in the advocacy process (6) Lack of adequate resources and (7) Countertransference issues. Clinical observations are integrated with the existing social work literature which focuses on providing services to AIDS patients.

INTRODUCTION

Persons suffering from Acquired Immune Deficiency Syndrome (AIDS) constitute a relatively new and expanding client group in

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need of social work services. Professional journals and conferences have responded to the growing need for knowledge and skills in serving AIDS patients (Furstenberg and Olsen, 1984; Kissel, 1987; Buckingham and Van Gorp, 1988; Lopez & Getzel, 1984; Dunkel & Hatfield, 1986; Greif & Porembski, 1988; Safyer & Spies-Karotkin, 1988). Translating this new knowledge into practice, however, is still a pioneering field of endeavor. Social workers in health care settings caring for large numbers of AIDS patients are establishing programs and accumulating clinical expertise in this area (Lopez & Getzel, 1984; Christ, Weiner & Moynihan, 1986). However, it appears likely that with the spread of AIDS, a growing number of social workers in smaller communities without established programs will be providing clinical and case management services to AIDS patients. Providing these services in the face of seemingly insurmountable barriers can be an exhausting task for the clinician.

This article is based on the authors' clinical experience with an AIDS patient. The authors do not purport to describe new insights, successful interventions, research results or innovative programs for AIDS patients. To the contrary, this article deals with problem areas and barriers. The purpose of sharing this material is to assist other health care social workers in identifying similar problems, barriers, and frustrations in providing help to AIDS clients. Case material is presented and seven different obstacles to effective case management are identified and discussed.

The case management of David, an AIDS patient, by hospital social workers during the terminal phase of his illness was quite complex and served as impetus for this article. His case history will be presented and obstacles to case management identified based on work with this client.

The Case Illustration. David was a single, black male in his mid-thirties, who was admitted to a cancer hospital for treatment of lymphoma and AIDS. He had held a responsible professional position in a large national firm, where he had worked since completing graduate training in his twenties. David had known of his AIDS diagnosis for three years and had been treated at several facilities. He never acknowledged a gay sexual orientation to anyone on the health care team. However, his charts from other hospitals stated that he had described himself as gay. He was receiving a disability income and had private medical insurance.

David was raised in a large family with conservative beliefs. Fearing their disapproval, he had concealed his diagnosis from all of his family members except for one sister, Josephine. Josephine was supportive of David but did not share his diagnosis with her husband, whom she believed would prohibit her contact with David if the diagnosis were known.

Keeping his diagnosis a secret from both family and acquaintances was of primary importance to David. For this reason he had moved 700 miles away from his home of ten years. He lived briefly with his sister, Josephine, but then deliberately sought a hospital specializing in cancer treatment in a neighboring state where he knew no one. His plan was to receive treatment during the terminal phase of his illness without the AIDS diagnosis becoming known to family or former friends. He informed them only of his diagnosis of lymphoma, a type of cancer common in AIDS victims.

OBSTACLE 1: THE STIGMA OF AIDS AND HOMOSEXUALITY

David was certain that family knowledge of his AIDS diagnosis would lead to total rejection of him, and thus he experienced shame about his illness. He was one of the gay patients described aptly by Lopez and Getzel (1984) who led an "in-closet" life-style. Such patients may put geographic distance between themselves and their kinship networks, thus depriving themselves of important sources of help during a health crisis. The programs described by Lopez and Getzel (1984) and by Christ, Weiner and Moynihan (1986) utilize gay self-help groups and gay volunteers to fill in the gap created by family alienation. Patients such as David, however, may not utilize gay support networks because they have not fully accepted a personal identity as gay. Also, driven by their quest for anonymity, such patients may go to hospitals in smaller communities where such AIDS support groups are not available.

The Case Illustration. The primary medical treatment for David consisted of radiation therapy to control symptoms arising from

nasopharyngeal lymphoma. Treatment was initiated as an in-patient with plans for out-patient follow-up. David stated that Josephine would take him into her home during periods when he could be discharged from the hospital. However, in telephone conversations with the social worker, Josephine expressed reluctance to provide a home for David or be actively involved in discharge planning. She was adamant that her husband not learn that David had AIDS. To protect this confidence, she asked the worker to call her only on Tuesdays, her day off, and not to send letters to the house.

OBSTACLE 2: LACK OF FAMILY SUPPORT

Social workers rely heavily on families to lend instrumental as well as psychological support to gravely ill patients. Family involvement is frequently an integral component of discharge planning and other case management tasks. With AIDS patients families may withdraw out of shame or fear of contagion. Keeping the AIDS diagnosis a secret results in isolation for family members (Greif & Porembski, 1988) and limits the family's ability to respond to the patient's needs (Christ, Wiener & Moynihan, 1986). In the present case, it was clear that the patient's sister was torn between her love for David and her desire to respect her husband's opinions. The worker was unable to provide emotional support to the sister due to distance and limited communication.

The Case Illustration. Shortly after David's hospital admission signs of confusion and forgetfulness were observed. He could not remember staff who worked closely with him. The content of one day's interview was forgotten the following day. Emotional lability was also noted. He would fluctuate from tearfulness and sadness to anger toward his caregivers to believing he would be cured.

Neuropsychological evaluation revealed severe memory deficits, mild deficits in concentration and visual motor skills and moderate general intellectual decline. The psychologist noted that David either denied or was unable to understand his cognitive deficits and that learning new material would be extremely difficult if not impossible. David was given a DSM-III-R diagnosis of Dementia associated with HIV.

OBSTACLE 3: IMPACT OF AIDS DEMENTIA

AIDS dementia has been observed in approximately 60-80% of diagnosed AIDS patients (Buckingham & Van Gorp, 1988). In the early stages of dementia, presenting symptoms may consist of apathy, mood disturbance, social withdrawal and psychomotor slowing (Buckingham & Van Gorp, 1988). The AIDS virus causes progressive damage to the central nervous system and results in symptoms of forgetfulness, confusion and hallucinations (Safyer & Spies-Karotkin, 1988). The clinical implications of AIDS dementia are enormous for the health care social worker. For example, like many AIDS patients, David was young, lived alone and saw himself as an independent and capable person. Although he was aware of some memory loss, he was not accepting of the possible need for supervised living arrangements such as an adult foster home or nursing home. This created a serious dilemma for the social worker who wanted to respect the client's dignity and right to self-determination yet who felt responsible for ensuring the client's safety and physical well-being. The client's participation in discharge planning was compromised as decisions he made during lucid moments were later forgotten and/or resisted.

Haney (1988) declared that "one of the most crippling aspects of AIDS is the loss of power and control over life that the infected person experiences" (p. 252) and made a strong case for empowerment. AIDS dementia, however, presents a formidable obstacle to the empowerment for which both clients and social workers strive.

The current social work literature offers little direction for clinicians working with AIDS patients with dementia. Although two authors cogently describe AIDS dementia (Buckingham & Van Gorp, 1988; Safyer & Spies-Karotkin, 1988), they do not discuss implications for case management of patients with advanced dementia. Writers who specify interventions to be utilized with this client population do not refer to dementia complications (Christ, Wiener & Moyniham, 1986; Furstenberg & Olson, 1984; Lopez & Getzel, 1984). This gap is particularly unsettling in light of reports of dementia in over half of AIDS cases.

The growing knowledge base and literature on practice and ethical issues related to dementia in the elderly provides insights which

may be generalized to practice with AIDS patients. Watts, Cassel and Howell (1989) describe the health professional's challenge as trying to preserve dignity and autonomy for demented patients while providing safeguards to their well-being. They conclude that "situations such as these call for interventions which are both medically and ethically creative, and the marshalling of resources to maintain the individual's autonomy for as long as possible" (p. 661).

The Case Illustration. As David completed his initial radiation therapy and his discharge from the hospital approached, the social worker attempted to make a suitable plan for living arrangements and follow-up treatment. With the social worker's assistance David was able to arrange to fly to Josephine's home for a brief visit. He returned for continued radiation, and the social worker arranged for him to stay in the hospital's guest quarters, a hotel arrangement in a hospital wing normally used by families of out-of-town patients.

At this point an uncomfortable stalemate had been reached. David continued to want to return to Josephine's home. His wishes to "go home to die" were given careful consideration. It became increasingly clear that Josephine did not want to assume responsibility for David's care. Some members of the health care team also questioned the ethical issues of placing an AIDS patient in a home where at least some of the family members were unaware of the AIDS diagnosis.

David's second choice was to live independently. In light of the AIDS dementia, however, the social worker felt that David needed supervised living arrangements such as an adult foster home or nursing home. This assessment was underscored by reports that David was found wandering in the halls in a confused state and that he had defecated on the floor in his room in the hospital hotel. David, however, refused nursing home placement and against the social worker's advice left the hotel and rented an apartment.

The social work staff continued to communicate with Josephine to educate her about dementia and its implications for David's care. It was also suggested that David was in need of a guardian to make decisions in his own best interests.

A dilemma is created in the hospital setting when there is no guardian and a patient lacks the capacity to make sound judgments

regarding discharge. Often this dilemma is resolved by having a legal guardian appointed by the courts. In order for this to be done, the patient must be deemed physically or mentally incompetent by a court appointed examining committee. Family members are preferred as guardians, but if they are unwilling to assume this role and the patient is indigent, it may be difficult to find an appropriate or willing guardian.

The legal procedures to declare incompetence and establish guardianship require a certain amount of time to allow for due process and protection of client rights. This time lapse may mean that a patient spends needless and costly days in the hospital without treatment. Another complicating factor in establishing guardianship occurs when the patient's mental abilities fluctuate and hinder accurate assessment of mental status.

OBSTACLE 4: ETHICAL DILEMMAS IN DISCHARGE PLANNING

Abramson (1981) and Blumenfield and Lowe (1987) have addressed ethical dilemmas facing social workers in discharge planning and offered models to assist clinicians in analysis of these dilemmas. Both models address conflicts between patient autonomy, or self-determination, and paternalism, or actions taken by the social worker in the patient's behalf when the worker believes the patient is incompetent to make informed choices. Abramson (1981) also deals with the social worker's responsibility to the family of the patient if they are to be considered a discharge plan option.

However, these models are incomplete as guides for social workers dealing with AIDS patients because they do not consider the health risks to caregivers, family or professional, especially if they are uninformed of the presence of AIDS and do not exercise precautions.

The Case Illustration. During David's stay in the hospital's hotel, which was operated through the social work department, several complaints were received from hospital staff. The environmental services staff charged with cleaning the feces off the floor

were upset about the risk to their own health and appeared to blame the social workers for allowing the patient to stay there.

Disease in the nasal area resulted in profuse nasal discharge. Many members of the health care team questioned whether AIDS could be communicated through this type of body fluid. Although reassured this was not believed possible, staff members were uncomfortable in disposing of the trail of tissues David left. The staff's uneasiness and irritation increased as David became more careless as the result of the dementia.

Several physicians and other staff voiced displeasure with the social workers' position that David's wish for confidentiality regarding his diagnosis should be respected. The physicians felt that the health of both medical and family caregivers should be given priority over the patient's desire for secrecy.

OBSTACLE 5: CONFLICTS IN THE ADVOCACY PROCESS

The social work profession encourages its members to assume the role of patient advocate, particularly in the area of hospital discharge planning (Lurie, 1982; Marcus, 1987). Furstenberg and Olson (1984) have offered suggestions on how clinicians can work with health care staff to resolve problems between AIDS patients and staff and promote the patient's well-being. Implementation, however, can be a difficult, complicated task. The social worker is called upon to advocate for the patient while simultaneously educating staff, encouraging a safe, healthy environment and maintaining relationships with staff and departments throughout the hospital. If the patients' behavior is unpredictable due to AIDS dementia, maintaining a safe environment and reassuring staff is an even more challenging task.

The Case Illustration. David's physical health deteriorated as well as his mental status, and he was readmitted from his apartment to the hospital. Several members of the family came to visit. David continued to be concerned that his family not learn of his AIDS and asked that the Infectious Disease Precautions sign be removed from the door of his room. The nursing staff stated they could not grant this request.

After visiting David, Josephine acknowledged that he would not be able to live alone. She concurred with the plan to find a suitable nursing home either near the hospital or near her home in a neighboring state. The social worker pursued plans for a nursing home placement, with the hope of finding one near Josephine. However, the state agency denied having a single nursing home which cared for AIDS patients. A local nursing home which would accept David was located. However, Medicaid funding was denied because David did not meet the state residence eligibility requirement. Home health care and homemaker services were also denied.

OBSTACLE 6: LACK OF ADEQUATE RESOURCES

Helping the patient and family to accept the need for supervised living arrangements had been a very difficult task. Locating agencies and settings which would accept an AIDS patient turned out to be even more difficult. The social worker spent many hours making telephone calls, completing paperwork and discussing the patient's needs with numerous agencies. It appeared that even agencies willing to serve AIDS patients did not want to be identified as such, perhaps fearing the stigma or an avalanche of similar referrals.

David's situation was complicated by his ineligibility for state funding. Other workers will probably encounter similar cases, however, when terminal AIDS patients move to hide their illness or "go home to die." The AIDS dementia was another complicating factor, as the nursing home or agency was being asked to take a patient who not only had a communicable disease but whose behavior was unpredictable.

Fear of contagion and the stigma of AIDS have resulted in many instances in which services are denied to this client population. Very few nursing homes will accept patients with AIDS. Some health care professionals and dentists refuse treatment to these patients as well.

Policy Implications

The lack of adequate resources confronted by social workers can best be addressed through advocating for changes in social welfare

and health policies which affect clients with AIDS. Suggestions for changes in three areas are offered.

Medicaid and Medicare Benefits

Continued efforts are needed to shorten the 24 month disability waiting period for Medicare benefits since many AIDS patients die before receiving these benefits. In the interim disabled AIDS patients with financial need may be eligible for the Supplemental Security Income (SSI) program which is accompanied by Medicaid benefits. When they become eligible for Social Security disability benefits, the increased monthly income makes them ineligible for Medicaid in some states. Some patients are not immediately eligible for Medicare, however, and for them the additional income does not compensate for the loss of medical care benefits. Clients would be better served if they were allowed to choose between medical benefits versus higher income based on their specific needs.

Nursing Home Care

Incentives such as higher reimbursement rates which would encourage nursing homes to care for AIDS patients should be considered. Another approach would be for regulatory agencies to refuse to license nursing homes, particularly new ones, unless the licensee agrees to take AIDS patients and in fact does so over a six month probationary period.

Dental Care for HIV Positive Patients

Access to dental care is a major problem. Many dentists believe they need a sterile environment to treat patients when in fact they do not. The American Dental Association (1988) has issued the following position statement:

> Current scientific and epidemiologic evidence indicates that there is little risk of transmission of infectious diseases through dental treatment if recommended infection control procedures are routinely followed.

State licensing agencies may need to put pressure on dentists to provide services to all persons as a condition of licensure.

The Case Illustration. David's illness reached a point where no further medical treatments were indicated. He was ready for hospital discharge but no suitable discharge plan was available. Informed of these bleak alternatives, Josephine appeared at the hospital with another of David's sisters who had offered to take him to her home. The discharge took place the same day after only a brief interview with this family member. The social worker tried to make a referral for hospice care in the community to which David moved, but none was available.

David died a relatively peaceful death about one month later. Josephine sent a Memorial Announcement and a letter describing David's funeral, the plans for which he had discussed with the social worker on several occasions. Josephine wrote of the family's good feeling about having provided care for David during his final days. She thanked the social worker for the help she had given David and their family.

Case Addendum: David's Social Worker's Notes

The primary social worker for this client was a newly graduated MSW. David was her first assigned case on a new job. She saw him as a fragile and defenseless person who was being physically ravaged by an unfair and unpredictable disease yet who was struggling to maintain integrity, control and acceptance from his family. In retrospect the social worker recalled a sense of tremendous responsibility for this client's well-being, perhaps because he was her first client or because of his fragility and helplessness or both. She felt that in her role of advocate it was her job to convince agencies and others in the health care system of their responsibility to assist this patient.

Through reading and discussions on AIDS the social worker was quickly reassured about her own safety and was comfortable working with David. She was frustrated, however, by having to deal with many prejudiced and irrational beliefs about AIDS among hospital and community service staff. Similarly, she was dismayed by negative comments in team meetings regarding David's pre-

sumed gay sexual preference. The worker was also aware of being angry with David's family for being uninvolved and unresponsive at times. She had to remind herself to be nonjudgmental in her interactions with them.

David became quite dependent on the social worker particularly as he grew weaker and confused by dementia. Although she understood David's anxieties and needs, the worker found she grew irritated when he constantly came by her office or asked nurses to call her several times a day. When she did see him, the interview consisted largely of conversations they had had several times before.

The social work supervisor questioned whether the worker may have felt angry with David for his steadfast refusal to disclose his diagnosis, as this request created much of the difficulty in dealing with the family. The worker, however, supported David's position fully and did not fault him for it. Having witnessed the negative reactions of staff to AIDS and homosexuality, the social worker accepted David's desire to protect himself from similar rejection from his family.

OBSTACLE 7: COUNTERTRANSFERENCE ISSUES

Dunkel and Hatfield (1986) discussed eight countertransference issues reported by social workers and other health care workers involved with AIDS patients: (1) Fear of the unknown (2) Fear of contagion (3) Fear of death (4) Denial of helplessness (5) Homophobia (6) Overidentification (7) Anger (8) Need for professional omnipotence. Of these issues fear of contagion and homophobia were readily apparent among various members of the health care team. The social workers were most aware of experiencing anger and the need for professional omnipotence. Fear of death was not a major issue among the staff in the cancer hospital as they often dealt with dying patients. Given the realities of prejudices encountered by AIDS patients it may be difficult to ascertain the dividing line between accurate empathy and overidentification. Fear of the unknown also appears to have a realistic component when dealing with an AIDS patient with dementia, as behavior is truly unpredictable.

SUMMARY

Although this article has focused on the barriers a social work clinician may face with AIDS patients, it would not be complete without mention of the positive aspects of these efforts. The social worker felt she learned patience, determination, professional humility and personal insights through her work with David. The case also included a myriad of social work roles, such as discharge planner, client advocate, counsellor and educator.

Even though the referrals to community agencies were unsuccessful, the social workers sensed that small changes were initiated in the health care system so that services might be developed for future AIDS patients. Although the ultimate outcome for AIDS patients is never a positive one, social workers can find some satisfaction in knowing that their professional skills can make a difference in these patients' quest for dignity, acceptance and needed services during the final stages of their lives.

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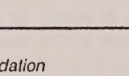

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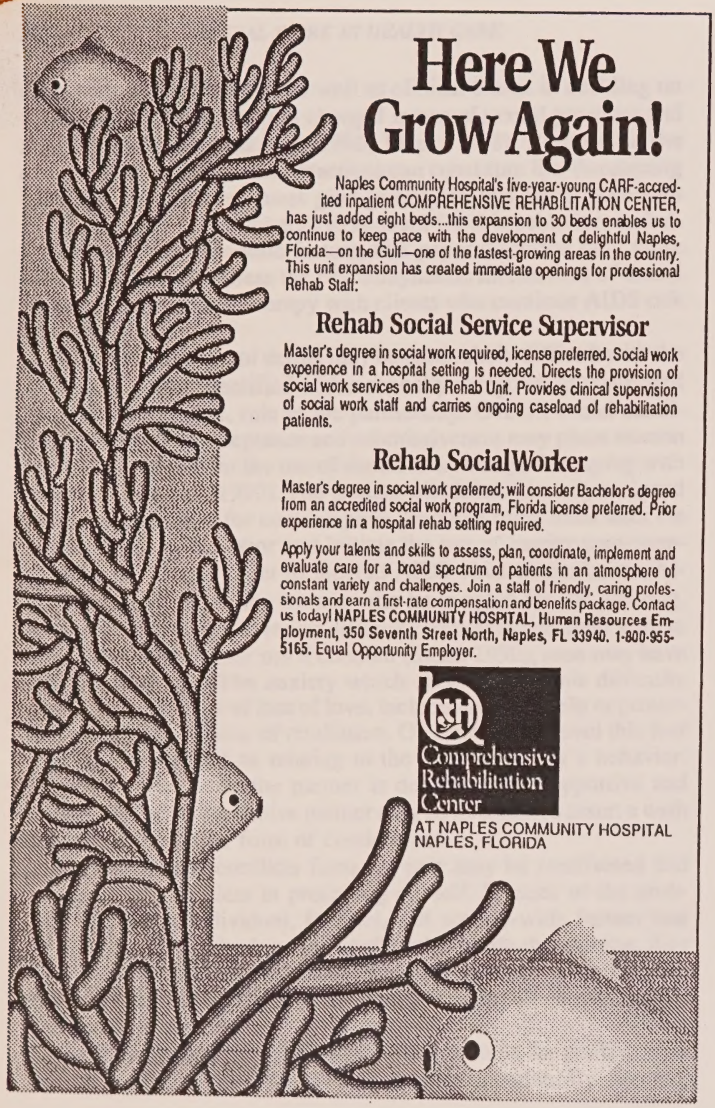

Working with Denial: A Critical Aspect in AIDS Risk Intervention

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ABSTRACT. Denial as a defense against anxiety can block the effectiveness of education and confrontation in work with clients manifesting AIDS risk behavior. The mechanism of denial is explored with reference to its role in supporting sexual acting out of unconscious conflicts. Clinical illustrations demonstrate the importance of work with denial as a prestage to effective AIDS risk intervention. Work with heterosexual and homosexual men and women is cited.

The advent of the current AIDS health crisis has focused attention on the dangers for those who follow unsafe health practices. Public health education programs have brought the facts about risk to the conscious attention of most clients who would be seen for treatment in an outpatient mental health care setting. Yet clinicians frequently learn about client behavior that does not reflect any integration of this information into the client's way of life (Siegel & Gibson, 1988; Rickert, Jay, Gottlieb and Bridges, 1989). On the contrary, many clients report sexual behavior in which protective strategies are entirely absent, and, when challenged, their absence is often justified. Additionally, clinicians themselves struggle with

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countertransference issues as well as clinical biases in deciding on ways to approach the highly charged issues of sexual practices and AIDS (Dunkel and Hatfield, 1986; Mack, 1988). Because, in the age of AIDS, unsafe sexual practices can constitute life-threatening behavior, the clinician must give priority to this issue. Although many variables may converge to account for this behavior, including cultural and economic factors, this paper discusses only those interventions that address the psychodynamic mechanism of denial as it appears in psychotherapy with clients who continue AIDS risk behavior.

Addressing the use of denial may be particularly difficult with the client who is self-identified with a sexually receptive, as contrasted to sexually assertive, role in the partnership. Overall social conditioning regarding acceptance and submissiveness may place women particularly at risk for the use of denial as a strategy for coping with anxiety (Campbell, 1990). The woman who is traditionally assigned more responsibility for contraceptive practices often must alter the usual pattern of behavior and initiate the use of barrier contraceptives by the man in order to prevent AIDS virus transmission. Although it is common for women who have opted for the pleasing, more submissive role to report difficulty with asserting their wish to have their male partner use a condom (Stein, 1990), men may have this problem also. The anxiety which accompanies this difficulty often involves a fear of loss of love, including loss of help or protection, as well as the fear of retaliation. On a conscious level this fear may be experienced as relating to the current partner's behavior. However, even when the partner is demonstrably supportive and caring, the more submissive partner may be reluctant to assert a wish for protection in the form of condom-use.

Unconsciously, conflicts from the past may be reactivated and reinforce this problem in protecting oneself. Sources of the problem may lie in individual, familial, and society-wide factors that have created a psychodynamic conflict that is life-threatening. Any education and/or role-modeling for safe sex practices may be blocked from internalization by defensive operations that deflect the intended impact.

Psychotherapy techniques offer valuable tools for dealing with the defenses as they emerge in the treatment situation. By directing

attention to the operation of the intrapsychic defenses that maintain life-threatening behaviors, the psycho-dynamically-oriented clinician can address the root of the problem. When continued risk behavior reveals that a psychodynamic process is in operation and when neither advocacy nor direct confrontation can alter this behavior directly (Adler & Myerson, 1973), the use of denial as a defense supporting that risk behavior should be considered. A better understanding of the dynamics of denial can enhance therapeutic work in this area and offers an approach to reducing risk behavior in the area of AIDS.

This paper is divided into three sections. First, there is a description of a recent research study and several clinical examples and vignettes to document the occurrence of denial and its operation specifically in AIDS exposure. Second, the defense of denial is discussed in terms of its unique features and its cooperation with other defenses in psycho-dynamic functioning. This discussion of denial is in accordance with the principals of intrapsychic conflict theory. Finally, case material illustrates clinical problems of work with denial as a defense, with reference to cases of AIDS risk in a heterosexual woman and a homosexual man.

ILLUSTRATIONS OF DENIAL IN AIDS RESEARCH STUDIES

A research study on AIDS denial behavior recently appeared in the *Journal of the American Medical Association* (Fischl et al., 1987). The study described twenty-three married couples in Miami who decided to ignore safe sex practices after one spouse was diagnosed with the acquired immunodeficiency syndrome (AIDS). After three years, all but two of the originally uninfected partners had converted to seropositive status. These originally healthy people, confronted with information about risk and an available means to avoid that risk, did not use their knowledge for self-protection. As a consequence, they acquired a fatal disease. These remarkable results deserve a closer look, since clearly psychodynamic processes may account to some degree for such a dramatically inappropriate response.

In this study, forty-five adults with AIDS and their spouses were followed to gather evidence for the heterosexual spread of human T-cell lymphotropic virus type III (HTLV III) infection. All spouses, children and household members were enrolled and examined at the time of the diagnosis of the AIDS patient, and were followed up every 4-6 months for 1-3 years. Seventeen of the identified AIDS patients were women, 28 were men and they ranged from 24-54 years old. Nine of the 45 identified patients used IV drugs, four were bisexual, four had received blood transfusions, two had hemophilia A, and nine were heterosexual with a history of either a prior sexual partner with HTLV III/LAV infection or a history of frequent heterosexual contacts. The seventeen remaining, who were without other risk characteristics, were Haitian immigrants. All of the couples had been married for at least one year. No risk factor for HTLV III/LAV other than contact with the diagnosed patient was noted for the originally healthy partners. At the time of enrollment in the study, ten couples no longer had any sexual contact following the diagnosis of AIDS in one partner. Twelve couples continued to have sexual contact with condoms, twenty-three others continued to have sexual contact without condoms. Of these 23 spouses who refused to follow safe sex practices, nine were positive for AIDS at enrollment, and twelve converted during the course of study (Fischl et al., 1987).

How does one account for these 23 couples refusing to use barrier contraceptives in the face of well-publicized evidence that they could infect or be infected by a life threatening disease? The defense mechanism of denial most likely plays an important role. The use of denial could account for the danger of AIDS being perceived, but its relevance having had no impact on behavior. The anxiety that would usually accompany recognition of danger could, in this way, be deflected or disarmed by intrapsychic means.

Vignettes from clinical work on an inpatient AIDS unit document the use of denial in the client's own words. A 28 year-old IV drug user was in the hospital for pneumonia. The social worker, assigned to do discharge planning, tried to speak with him about his housing arrangements. He refused to return to his wife because she had denied him unprotected sexual contact since his diagnosis as HIV+ 3 years earlier. When the social worker, a woman, counseled reconsideration of his priorities, especially in the face of his fragile health, he responded "I'm still a young man and I have my needs." When she pressed the issue, the client made sexual overtures to her, saying "Hey, you must like all this sexy talk; I can take you on and two of your girlfriends." This bravado illustrates the client's denial of his own HIV status as well as the risk he represents to any sexual partners.

Another heterosexual client, struggling with an intensely destructive and humiliating relationship with his mother, often pursued young, street-seasoned women prostitutes. After periods of daily unprotected sexual intercourse, he would become terrified of AIDS exposure and seek to have his HIV status tested. When he received a negative laboratory result, he promptly felt relief. This feeling was accompanied by accelerated claims of being dominant over women after all. Effective knowledge of his very real exposure to AIDS which he risked with known drug-using prostitutes would be submerged again; denial was the primary defense mechanism converting his experience of vulnerability to one of potent immunity.

A third client, a homosexual man, was compelled repeatedly to seek anonymous anal sex in notorious areas of an urban park. His psychotherapist struggled with his client's conscious manifest wish to stop this recognized self-destructive pattern. Every time the client became anxious, however, his compulsion to act out in this way overwhelmed his conscious resolve to stop himself. Interpretations about his search for intimacy and attendant mobilization of self-hate after his experience, slowed his activity, but confrontations of risk behavior alone did not help him control his compulsion.

In all these brief examples, there was no lack of information, cognitive capacity, or judgment about risks involved. Intense feelings of anxiety, anger, and longing mobilized the defensive use of denial, enabling sexual acting out to occur. Advising the client to attend to the dangers of the acting out was unsuccessful; denial dismantled the clients' ability to appraise danger in a way that mobilized self-preservative behavior.

Freud (1916, 1926) labelled anxiety based in reality assessment as signal anxiety, and located its dynamic seat in the self-preservative instincts. This self-preservative instinct gives rise to ego func-

tions which make actual self-preserving choices possible. Anxiety alerts the ego to make needed alterations to meet new danger. These adaptive alterations involve increasingly sophisticated appraisals of the nature and source of danger, and of efficient routes to its reduction. Interpersonal skills, judgment, logical sequencing, and related ego functions result. Anna Freud (1946, 1965) expanded understanding of the defenses, noting that when the danger is from the superego, moral anxiety ensues. As with signal anxiety, moral anxiety stimulates complex internal strategies to deflect, avoid, or ameliorate the perceived danger. The ego defensive repertoire evolves through this process. It is through these defensive processes that the ego is able to regulate the flow of anxiety and keep it at a level that permits adaptive responses to danger.

By contrast, annihilation anxiety is that which arises when the danger is to the ego itself, and the ego must respond not with growth but with the sacrifice of part of its own functioning. Developmentally arrested and/or regressively activated primitive levels of functioning occur. Alterations cannot be made through sophisticated combinations of higher level defenses such as isolation of affect, reaction formation, and selective forms of repression. Consequently, anxiety in the face of the actual danger appears uncontrollable, escalating to annihilation levels, and must be defused by altering ego functions. Denial is one of the defenses that permits altering reality testing to avert its psychological impact.

In the case of the participants described in the research study and the clinical vignettes, anxiety that would be expected to have triggered self-preserving solutions, such as condom use, was disarmed. Rather than suffer intractable anxiety associated with initiating the behavioral changes to have safe sex, an unconscious compromise was struck in which anxiety was avoided by denial of the immediate danger of AIDS in continued barrier free sexual contact with known or suspected infected partners. A therapeutic intervention would need to address the latent processes that convert the danger signal into intense annihilation anxiety and thereby incapacitate normal ego functions. To do this, the defense of denial must be made unnecessary or less necessary.

DENIAL AS A DEFENSE MECHANISM

What is denial? What is denied? Freud's (1938) view was that "the ego often enough finds itself in a position of fending off some demand from the external world which it feels distressing and that this is effected by means of a disavowal (i.e., denial) of the perceptions which bring to knowledge this demand from reality" (pp. 203-204). What is denied, therefore, is external reality. Protecting oneself from forms of internal danger takes precedence over danger from external reality. Reality is perceived, but the meaning is disowned. The ego functions of reality testing and logical sequencing are compromised, but the result is a preservation of core ego integrity against the onslaught of what otherwise could be experienced as a threat of annihilation.

One of the most comprehensive examinations of this ego defense mechanism was conducted by The Kris Study Group in their monograph on "The Mechanism of Denial" (1969). To briefly summarize their conclusions: "denial occurs in response to the ego's requirement that it reconcile reality to instinctual strivings and superego demands. The dynamic impetus for its action arises out of adaptive needs related on the one hand to narcissism and on the other to object relations" (p. 53). Anna Freud (1965) suggested that denial may be a prestage of defense, the basic substratum for all defenses. This indicates that it is not the presence of denial which in itself causes a problem. Rather, over-extension of its use, or its dominant use in specific areas can jeopardize development of more adaptive defensive strategies which do not distort reality. Denial operates naturally in early childhood before boundaries between the ego and id and between the ego and the external world are firmly established. It is seldom observed in pure form except in children and occasionally in psychotic patients. As Anna Freud noted (1965), denial, by itself, is an ineffective defense and it does affect the person's perceptions of reality. To sustain a core of denial, a host of secondary denials may be developed. Other kinds of mental phenomena can bolster denial, including negation, fantasy in word and act, dreams, distorted memories and character traits. In addition, screen memories, doubting, questions, and some forms of lying may represent persisting attempts at denial. For

most adults, denial is found operating alongside these other defensive activities and is called upon to handle anxiety that otherwise would overflow.

An example of the interaction of denial, projection and isolation of affect is found in the case of a woman who discovered a lump in her breast. Rather than seeking medical advice immediately in response to this discovery, she decided to wait until her physician returned from his lengthy vacation, and then she made an appointment to see him several weeks later. What happened to the anxiety one would expect her to feel in a cancer-threatening situation like this one? The woman was cognitively aware that she had a lump, but she denied its relevance as a life endangering discovery. She separated factual awareness of the danger from the implication that the lump, if malignant, would be likely to grow during the intervening weeks and affect her treatment options later on. Aiding denial and isolation of affect was the defense of projection. While the woman herself experienced no anxiety about her condition, she was upset and angry with relatives whom she experienced as intrusive and over-reactive about her discovered lump. That which was denied (the danger of cancer and attendant anxiety) was experienced as residing in the external world (her relatives) and not in herself. She also appeared to have constructed a fantasy, using denial to equate the absence of the medical person, her doctor, with the absence of medical urgency to attend to her condition.

For some women, whose capacity for relatedness has been identified as an enhanced attribute of femaleness (Gilligan, 1982; Chodorow, 1978), disruptions in intimacy may have heightened impact as a source of denial-inducing danger. Knowledge of the emotional indifference of an important other can be denied to protect against a threat of losing that vital object relationship. Reaction formation and isolation of affect are defenses that can assist denial by stimulating conscious-level self-blame. Immersion in outside activity can be enlisted as way to help conceal the evidence of emotional abandonment. For instance, a woman, now divorced, saw no significance in the fact that she wore both her own and her husband's wedding bands after he decided to remove his permanently. Denial also can be used to defend against the threat of an actual object loss as in the example of one man who continued to buy birthday presents for his wife years after she had died. Physical evidence, like the absence of a ring or of a routine, or the presence of a lump or of a barrier such as a condom, can be powerful emotional triggers which evoke the need for denial.

Treating denial in the clinical process requires the painstaking uncovering of the sources and forms of anxiety which support the continuing need for this primitive defense mechanism. The persistence of denial as a defense often occurs when early anxiety-management strategies were insufficient to the child's level of stress-exposure. Additionally, massive stressors in the present may set off a regression to a level where ego boundaries are eroded in the adult. Since sexuality involves regression in the service of the ego, the ego-id boundary may become blurred in a way that summons denial. The issue of the psychotherapist's countertransference is particularly important because treatment requires balancing the urgency of helping clients protect themselves with the slow and purposeful process of working through denial and its ancillary defenses. As the cases below illustrate, efforts to shortcut this psychodynamic process in the treatment, however well-rationalized by the urgency of the situation, can end in stalemated treatment or client flight from treatment.

CASE EXAMPLE: RICHARD

Richard is a 36 year old homosexual man who entered treatment for reactive depression following the death of his father. He had given up his job and moved in with his widowed father to nurse him through a terminal illness related to years of alcoholism. His mother, a possessive and dependent woman, had died when he was in his twenties. The youngest of 6, Richard assumed the care of his father, including regulation of his medications and hygiene, providing emotional support, and maintaining a home for the two of them. During these years he was celibate. For the preceding decade he had been promiscuous, often with I.V. drug users. While acknowledging a risk of exposure to AIDS, Richard expressed the certainty that he was absolved by his "clean" years and devoted service.

During the first three months of therapy Richard focused on his feelings about his father and his loss. As the depression began to lift, Richard became interested in establishing a new love relationship. He began seeing James, a man ten years his junior who quickly moved in with Richard and filled the caretaking and companionship void left by Richard's father's death. It was within the developing sense of security in this new relationship that Richard first voiced his concern about his HIV status. He spoke about the possibility of being tested. Concurrently, a new problem arose for Richard which brought escalating anxiety and regressive defenses into the treatment picture. Richard's lover decided that he wanted to have other sex partners. Up until this time, Richard had agreed to be monogamous and enjoyed barrier-free sex. James' decision to end their monogamous relationship left Richard torn between his fears of losing his lover if he protested James' decision and/or exposing himself to further AIDS risk if he continued to stay with James. His either/or formulation activated feelings of intense helplessness. The associated anxiety mobilized a regression to earlier modalities of defense, in particular denial. Richard anticipated an emotional death if James left him; this overpowered the fear of possible death associated with AIDS risk. His fear of the loss of his relationship with James was much more compelling than his fear of death by infection. The possibility of life with another lover, or of working to convince James to change his behavior, did not exist as psychological reality for Richard. This replicated his experience of impotence when trying to engage his parents to respond to his needs during childhood. His capacity to use his judgment in his present relationship was clouded by past object relations configurations in a way that changed signal anxiety into annihilation anxiety. This, in turn, mobilized the intrapsychic defense of denial. Clinically, the task was to make these distorting processes evident so that Richard could use his otherwise intact ego functions.

The therapist offered genetic reconstructions about abandonment fears in childhood, citing how the options available to him when he was small differed from those he had available to him as an adult in his present situation. The therapeutic aim was to make the behavior ego dystonic, opening the door to new options for self-protection while still being in an intimate relationship. Quite literally this could mean freedom to use condoms. In the transference Richard appeared to experience the therapist increasingly as the mother who was thwarting him. A dream at this stage portrayed women coming to tell him he'd "missed graduation." While he said this meant unfinished business in therapy, he nonetheless decided to interrupt treatment vowing to return at some future date.

Although many psychodynamic currents converged around his leaving treatment, the most powerful was Richard's need to deny his risk behavior in order to maintain his relationship with James. In his view, his connection to James was threatened by the reality of his therapist's confrontations, so he left the therapist.

What had not been adequately established as a prelude to the confrontation over safe sex practices was an exploration of Richard's capacity to survive in the face of annihilation fears. Richard had never completed the task of defining himself as a fully independent and autonomous man. The earlier death of his mother and more recent death of his father, led to the activation of early developmental deficits. His depression masked severe anxiety about being able to survive alone. Even though Richard's precipitous attachment to James was clearly a flight into a new dependency, a more conservative therapeutic strategy might have helped him complete the mourning of his father and earlier loss of mother. The denial of his vulnerability in the present reinforced denial of the earlier fears of annihilation which had been brought close again by his father's death.

This case exemplifies how education or confrontation about safe sex may only partially address the complex psychodynamic processes that motivate risk behavior. When the clinical focus is too exclusively on manifest issues, the therapist is unable to reach the deeper unconscious anxieties. The safe sex issue, itself, was defensively structured for Richard. Wishes and fears about vulnerability and dependence were encapsulated in the risk behavior struggle. Long-term psychotherapy would be required for Richard to work through his infantile experiences of intolerable anxiety. This process would be necessary to dismantle the use of denial as a defense and to open the possibility of an intimate relationship in which gratification and nurturance were reciprocal and not linked to infantile dependency needs.

CASE EXAMPLE: HELEN

Helen is a 23 year old woman who fled from a small town in Maine to the excitement of fashion-industry work in New York City. She attached herself quickly to John, aged 42, who helped set up her career but demanded adoration and submission in return. A histrionic personality style masked her dependence and underlying depression. When anxious she became increasingly flighty and avoidant. Demands by John to attend to his needs made her anxious, as she felt herself being swept up into his world. Her need to deflect his demands, in order to preserve a sense of her own personal identity, became more pronounced, and John became angered by her rebelliousness. Helen's flirtatiousness and elusiveness had served her well until the present. She had coped in adolescence with an increasingly paranoid and threatening father who subsequently became psychotic. Unable to sort through her own identity issues in adolescence, Helen had been preoccupied with ways to keep the lid on the deteriorating psychosocial climate at home. Her mother was ineffectual and ignored her husband's growing bizarreness. Her father's decline had begun following her mother's return to work when Helen was around ten. He accused her mother continuously of disregarding him. He finally left the house, and Helen became his conduit to the family. She constantly feared the telephone ringing and someone saying, "It's about your Dad. . . ." as a prelude to disaster. Her legacy of anxiety over intimacy with a man was managed defensively by intrapsychic means as well as interpersonal gamesmanship. Helen fled home at the first opportunity. Although she functioned in a precocious, independent style, Helen was psychologically still immature and latched onto men for support. However, her conflict over dependence/independence led her into provocative and silly forms of defiance, rather than clear articulation of a position of her own.

Helen was in effect brought to treatment by John after a violent outburst on his part. He was, quite appropriately, scared by the excessiveness of his angry attack on Helen. She appeared manifestly unconcerned. Having delivered her to the therapist, John promptly broke off their relationship, leaving Helen to fend for herself for housing, social contacts, and financial security. Helen found another man within 24 hours, and then a series of men, with whom she fell "in love." She eagerly sought sexual intercourse as soon as possible as a way of securing the man. She wanted him to "need" her sexually so she could feel secure in needing him emotionally. All barriers were to be swept aside. She continued to see her therapist, hoping therapy would help her "do better with men." In treatment, Helen's issues in her interaction with men were regularly discussed, so it was not difficult to inquire about how she handled sexual contacts and attendant risks. She was aware cognitively of risk practices and informed about prevention. Yet Helen continued barrier free sexual contact with multiple partners. When the therapist asked how Helen thought about this apparent contradiction between her stated appraisal of what to do, and her actual practices, Helen could not explore the issue. She returned instead to recount anxiously and amusingly the details of her efforts to seduce the latest man. The therapist assessed Helen's capacity to use higher order defenses as fragile: she could only intermittently reflect on her behavior. Reflection became altogether impossible when a conflict with a man predominated. At other times, between her affairs, Helen seemed lost and almost inarticulate. This state seemed to replicate the alternative of formless and bland relatedness with mother as the alternative to confusing but intense relatedness to father. The therapist seized on this kind of hiatus in Helen's anxiety as the time when construction of an identity of her own could begin. When Helen was at a loss as to what to say, the therapist asked her to relay more about her background, her feelings about various friends and colleagues other than with lovers, her family, her ambitions in work, her love of sewing, what was fun, and any other subject which required Helen to deepen and enrich her feelings and awareness of herself as her own woman outside the sphere of sexual relations with men. Consequently, Helen began to describe dreams in which disturbing, unbidden experiences of sexual intercourse were interspersed with wished-for affectional and playful ones with a man.

By elaborating ways to seek self-expression and assertion of her own needs, Helen gradually reduced her pursuit of definition through satellite experiences with a man. Her sexuality which had been organized around submissiveness and domination became less

salient, opening the door for more frank discussion between Helen and a man. Only at this point in the clinical process was Helen able to consider a behavior change regarding AIDS risk. Unlike the client Richard, whose early loss of mother and recent loss of father had set the stage for primary fears of abandonment, Helen's fears revolved around retribution by the man for the woman's achieving power of her own. Denial of her own position had enabled Helen to push aside the potential of conflict with men, as she had with her father. From this defensively maintained position of non-individuality, it had been impossible for Helen to ask for a change in a man's behavior, such as to use a condom. Clinical work to enhance defensive flexibility and object relatedness had made anxiety about self-assertion more ego dystonic. Anxiety about self-assertion in sexual practices also became dystonic. Helen then could assert her identity in ways that could ensure her health and safety.

CONCLUSION

While educational efforts and the technique of confrontation in psychotherapy have an important place in enhancing clients' effective self protection against AIDS risk behavior, in many instances they may be insufficient. In such cases a regressive activation of denial as a defense may present a clinical impasse. When denial does occur, psychotherapy needs to attend to reducing the anxiety which is fueling the self destructive behavior and maintaining the defensive denial of AIDS risk in the face of cognitive awareness of the implications. The two extended vignettes presented illustrate denial defending against anxiety over abandonment in one case, and anxiety over retribution in the other. Clarifying the historical meaning and context of the client's anxiety in an effort to make it ego dystonic can free the client to choose more self enhancing, self protective behaviors.

Clinicians concerned about AIDS risk behavior in their clients need not, and indeed often should not, abandon the basic tools of exploration and understanding in order to address this critical health issue for clients. Rather, a judgment as to the most efficient

route to this material can flow from dynamic assessment of the risk pattern itself and the core anxieties linked to defensive denial which supports that behavior. The treatment relationship must contain evidence that the client has identified with the therapist's wish for him/her to be safe as well as relieved and gratified, as a prestage to direct work with denial. This wish can be observed as active in the client when conflict between self-preservative and self-expressive aims are expressed as internal rather than interpersonal. The therapist may then work to pinpoint the exact situations where these conflicts erupt. In the case of Richard, a therapeutic impasse arose when his anxiety took the form of a transference reaction: the therapist became the thwarting mother rather than the nurturing mother. This undercut his ability to identify with the therapist's wish for him to take care of himself. By contrast, Helen could identify with the therapist's concern for her health and safety. The therapist's intervention in the form of expressing interest in how she was being rather than what she was doing evoked less conflict for Helen, leaving room for a strong working alliance to develop alongside the transference. The secure relationship boundaries defined by this working alliance made anxiety in the specific area of AIDS risk behavior manageable without ego regression.

To set the stage for dismantling the self-destructive functioning embedded in the denial of AIDS risk, preliminary work on broader anxiety themes may be necessary. To the extent the behaviors which are now AIDS-exposing have been culturally and/or socially congruent, anxiety linked to identity themes, not only separation from family, may need to be factored in by the therapist. For any individual, direct confrontation of the defense of denial will be premature if the transference does not indicate strong positive alignment between the therapist and those aspects of self the client is aware of wanting to preserve. Otherwise, self-preservation will be experienced more in relation to the unconscious anxiety than to conscious risks. Efforts to short-cut this often laborious preparatory work with anxiety themes, while altogether understandable given the health crisis involved, can derail the treatment objectives and leave the client with the use of denial intact.

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Obstacles to Effective Case Management with AIDS Patients: The Clinician's Perspective

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ABSTRACT. A social work clinician filled the role of case manager with multiple functions of discharge planner, client advocate, counsellor and educator in her work with a young male AIDS patient and his family. Material from this case is used to illustrate seven problem areas identified as obstacles to effective case management: (1) The stigma of AIDS and homosexuality (2) Lack of adequate family support (3) Impact of AIDS dementia (4) Ethical dilemmas in discharge planning (5) Conflicts in the advocacy process (6) Lack of adequate resources and (7) Countertransference issues. Clinical observations are integrated with the existing social work literature which focuses on providing services to AIDS patients.

INTRODUCTION

Persons suffering from Acquired Immune Deficiency Syndrome (AIDS) constitute a relatively new and expanding client group in

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AIDS Case Management

A Model for Smaller Communities?

by Eleanor Littman & JoAnn Siemsen

The AIDS epidemic has exposed for the public the shortcomings of long-term home care such as inadequate reimbursement, limited availability of qualified personnel, and lack of coordination of multiple services. Because these shortcomings in home care result in more hospital days for AIDS patients, national, state, and local AIDS Commissions are all looking for solutions. AIDS case management is more and more frequently recommended as the answer. This groundswell of support for case management provides an opportunity for the home care industry, which has extensive experience in case management, to establish standards for AIDS case management.

The experience of Hospice Caring Project of Santa Cruz County indicates that each community must establish its own standards for AIDS case management based on the needs of its AIDS patients and the characteristics of the local health care system. This article provides some background information on the evolution of AIDS case management in San Francisco, and then state-wide in California, and the application of AIDS case management in Santa Cruz County, a California community located outside of a major metropolitan area. The purpose of providing this information is to enable home health care providers to better contribute to their own community's discussion of how to respond to the AIDS epidemic.

Background

A study of AIDS patients treated at San Francisco General Hospital (Scitovsky, Cline & Lee 1986) has influenced the growing public consensus that expanded home care reduces hospital days. Lifetime costs for AIDS patients in San Francisco were found to be lower than in other areas due to a per patient average of 35 hospital days, versus 168 reported in a national study (Hardy, Rauch, Echenberg, Morgan & Curran 1986).

Scitovsky, Cline, and Lee attribute some

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of this difference to differences in patient mix—primary male, homosexual patients in San Francisco as compared to a mixture of both homosexual and intravenous (IV) drug users in other areas. But after examining the clinical differences in the populations, the authors conclude that the principal reason for San Francisco's lower medical costs is the well-organized gay community in San Francisco. The recommendation to other communities is "that costs of treating patients with AIDS can be reduced substantially given community support services that help to keep patients out of the hospital so far as medically possible" (p.3106).

However, the Scitovsky, Cline, and Lee study has limitations when applied to home care services planning. The study did not estimate the inpatient substitution cost of community-based services such as home nursing, attendant care, special residential and hospice services, nor the economic value of volunteer support. The study also did not evaluate the cost of care of the approximately equal number of San Francisco AIDS patients who choose to be treated on oncology or general medical surgical units at private, community hospitals and by private physicians. Consideration of this patient category would answer the question of whether community-based care can be cost effective outside of the San Francisco public AIDS service delivery system.

Who's Swimming in Circles

Notes from an AIDS Nurse Case Manager

I first met "Fish" after he had been hospitalized for two months. He was referrec for AIDS case management by the hospital discharge planner who needed help getting him out of the hospital. I call him Fish because from when I first met him he reminded me of a fish in a fishbowl—going round in circles and with all of us on the outside peering in and shaking our heads in frustration.

Fish was a 39-year-old gay man who had worked for a major US corporation. He had been diagnosed with HIV disease two-and-a-half years earlier. After his diagnosis, he declined medical followup, quit his job, began abusing drugs, and decided "to see the world before he died." In Southeast Asia he got sick and called his parents to bring him home.

Home was Santa Cruz, California. He began medical care, albeit half heartedly. He didn't like AZT, didn't comply with prophylactic treatment of Acyclovir and Nizoral, and again fell out of medical treatment as his drug habit escalated. His parents became increasingly frustrated with his lack of compliance with medical care, heightened drug use, increasingly bizarre behavior, such as going out all hours of the night, not returning home for days, and picking up any sexual partner available. Despite appeals from family, friends, and physicians, Fish continued to deny his illness and became a public health threat.

His family gave up when Fish became psychotic, suidical, and physically threatening to them. He was hospitalized by his physician for HIV dementia exacerbated by drug abuse. In the hospital Fish flipped back and forth between the medical/surgical and the psychiatric unit as his physical status changed. After two months of constant monitoring and medication administration, Fish's mental status cleared, he had no acute physical symptoms, and he was able to care for himself with minimal assistance. In other words, he was a candidate for discharge from the hospital. But where could he go?

He had no caregiver: his terrified parents refused to take him back. His dramatic recovery in the hospital had demonstrated that he needed monitoring and regular medication administration to prevent a recurrence of the acute symptoms of his disease. The hospital discharge planner asked for the assistance of the AIDS case manager, public guardian, public health nurse, and AIDS Project volunteers to find an appropriate supervised residential setting. For four months this group met weekly to compare notes and leads. Each member then spent many hours following up on possible residential programs.

No supervised residential facility would take Fish. The mental health system denied placement in any of their residential facilities because his "organic diagnosis of HIV encephalopathy" was outside their guidelines. Private licensed residential facilities had contracted all their beds either to the mental health system or to persons over 55. One motel did agree to take Fish, but the motel was unsupervised and had a history of drug activity. The public guardian who had legally conserved Fish early in his hospitalization refused to allow him to be discharged to the motel.

Fish excluded himself from drug treatment programs because he would not acknowledge that he had a drug abuse problem. He could not be admitted for detoxification because after months in the hospital he was not actively using drugs.

Fish had no home to go to and not enough income to support himself. The AIDS Case Management Project had some supplemental funds for housing or for attendant care, but not enough for both. In addition there were no attendants available with experience supervising mental health patients.

There is no inpatient hospice program in the county, and even if there was it was not certain Fish would qualify as terminal with his fluctuating physical and mental symptoms.

The hospital tried to put pressure on the system by threatening to discharge the patient to a bus stop. The only agency that responded to this threat in any way was the public guardian who decided to deconserve Fish so the hospital could place him in the motel and they would not be responsible for what happened.

For six months, multiple players—staff of the hospital, the AIDS Project, Hospice, mental health, public guardian, and the health department, along with a visiting priest and family members—circled through Fish's hospital room trying to come up with a solution. After six months in the hospital, Fish was starting to show a regression in his mental status which the psychiatrists thought was due to the "confined prison-like feeling he was experiencing." At this point he unexpectedly developed kidney failure and died quite suddenly.

Nothing has changed in the health care system since Fish's death. Although I originally thought of this patient as "the Fish," I now wonder if we may not be the one's stuck in a tank. ■

Contributed by Elaine Beardsely, BSN, RN, OCN, AIDS Nurse Case Manager, Hospice Caring Project, Santa Cruz, California.

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San Francisco Health Services Model

The San Francisco model of care for AIDS patients has been described in numerous reports as a community-based system designed with the principal objective of avoiding hospitalization whenever possible.

Six key elements of the San Francisco model are commonly identified:

- a dedicated inpatient unit at the public hospital staffed by nurses, physicians, social workers, and volunteers with recognized state-of-the-art expertise in the care of AIDS patients;
- an AIDS outpatient clinic, also at the public hospital, staffed by oncologists, infectious disease specialists, nurses, social workers, and volunteers, all of whom care exclusively for AIDS patients;
- high-technology home health care and hospice services including IV antibiotics and chemotherapy;
- skilled nursing facilities and residential hospice care for AIDS patients requiring this level of care;
- community-based counseling and practical and emotional support service programs staffed primarily by volunteers;
- education and prevention programs for high-risk populations, transportation services, and emergency or long-term residential facilities.

In addition to these elements, it is also important to note that as early as 1982, the San Francisco Department of Public Health began to assist in the organization and funding of home care services for persons with the human immunodeficiency virus (HIV). This leadership by the health department has created a continuum of services and reduced duplication.

With supplemental funding from the city of San Francisco, Visiting Nurses and Hospice of San Francisco began the AIDS Home Care and Hospice Program in 1984 and has been very effective in reducing hospitalizations for AIDS patients using a multidisciplinary case management team based on the hospice model of care (Hughes, Martin & Franks 1987).

California Case Management Model

In 1985 the California legislature, eager to spread the success of San Francisco in containing the costs of AIDS care to other areas of the state, authorized the state Office of AIDS to begin a state-wide demonstration of case management and home care services. The request for proposals states that "effective case management can help to establish high-quality care to AIDS patients and reduce the medical care costs by assuring that appropriate care is provided in the appropriate place, by the appropriate providers in the most appropriate and cost effective manner" (Fraziear 1987, cover memo). Funding was provided for case management as well as for home care services such as food, housing, and attendant care.

The request for proposals defined core case management activities as outreach/intake, evaluation/assessment, service planning, implementation, and monitoring/follow-up/evaluation. Four specifications were built into the California model:

- The case manager must be a registered nurse with at least a bachelor's degree, three years of public health experience, and expert knowledge of AIDS/ARC (AIDS-related complex).
- The case managers are required to maintain telephone contact with their clients at least weekly, and in person at least monthly.
- The case manager or project director must authorize all expenditures for home care services.
- Because the project is principally a research and demonstration project, data on client status, services used, and costs must be submitted on a monthly basis.

It is important to note that the California program deviated from the San Francisco model in two significant ways: (1) it provided no funding for community-based services that were not home based (eg, residential hospice); and (2) it did not specify linkages between home care, inpatient, and outpatient care.

The initial projects funded were in the major metropolitan areas of California (especially Los Angeles), and the majority of the case management agencies were community-based AIDS organizations, not licensed home care agencies. Based on the experience of these initial AIDS case management projects, two additional specifications were added to the California model:

- The case management agency should subcontract for home care services (including intermittent nursing visits) from other providers, whenever possible.
- The nurse case manager should not provide direct nursing care and should carry a caseload of 30–35 patients.

In 1987, in recognition of the spread of AIDS outside the metropolitan areas, the state Office of AIDS began soliciting applications from communities with lower AIDS incidence. Hospice Caring Project was awarded funding to apply the California

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AIDS case management model in Santa Cruz County.

Small Community Case Study

Santa Cruz County is located on the central California coast and has a population of approximately 225,000. Although only 70 miles south of San Francisco and 25 miles west of San Jose, there is no interstate connection to either metropolitan area. As a result, the health care system in Santa Cruz is remarkably self-contained.

Since 1981, 93 cases of AIDS have been diagnosed in Santa Cruz County, of whom 41 are still alive. This number does not include AIDS patients cared for in Santa Cruz County who have been diagnosed in other counties, or patients who are HIV positive but do not meet the Centers for Disease Control's definition of AIDS. Local physicians estimate there are currently 150 persons in Santa Cruz County who are HIV positive and are being treated for symptoms of their infection; a 1987 study by the county health department estimated that at the time there were an additional 1,170 patients who were HIV positive but not symptomatic.

The number of AIDS cases grew slowly between 1981 and 1986, and by 1987 AIDS was officially recognized as a significant local health problem. Since 1987, the number of cases has more than doubled (39 to 93), and, despite the low numbers, the incidence of AIDS in Santa Cruz County is now greater than that of the neighboring San Jose metropolitan area.

As is true in many communities outside of major metropolitan areas, Santa Cruz County has limited public health care services, and patients with AIDS must rely for services on private hospitals, individual medical practitioners, and private social and health services agencies. All of these providers serve the general population; to date none have had sufficient AIDS patients to develop specialized programs. For example, all three private hospitals serve AIDS patients, but none has a sufficient number of patients to specifically designate beds or a unit for the AIDS patient. The differences between the Santa Cruz and the San Francisco health care system in 1987, at the time the application was made, are summarized on Figure 1.

Hospice Caring Project of Santa Cruz County (hereafter referred to as "Hospice") is a licensed home health agency and Medicare certified for hospice services only. As such, it serves patients with a primary caregiver in the home and a prognosis of six months or less. As a licensed agency, Hospice provides a full range of skilled home care, volunteer support, and bereavement services.

By 1987, Hospice had cared for only nine AIDS patients, but because that was more than any other health service agency and because Hospice had established a reputation for compassionate AIDS care, the Santa Cruz AIDS Project and the health department asked Hospice to apply for state funding for AIDS case management. The Hospice board of directors agreed in order to expand services to current and future hospice patients with a diagnosis of AIDS, as well as to serve AIDS patients who did not have a primary caregiver and/or whose prognosis was longer than six months but were nonetheless facing a terminal diagnosis. Hospice was awarded funding for AIDS case management beginning in spring 1988.

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Figure 1
Comparison of AIDS Health Care Delivery System in San Francisco and Santa Cruz, California, 1987

SERVICE	SAN FRANCISCO	SANTA CRUZ
Inpatient	Dedicated unit; public hospital	Private hospital beds as available
Outpatient	Public AIDS clinic; physician specialists managing only AIDS patients	Private physicians; only one internist with more than 10 patients
Home Care	Sophisticated, high-tech home care and hospice services	Little high-tech home care; no local home IV program; newly licensed hospice
Residential	SNFs and residential hospice programs for AIDS patients	Only hospital-based SNF willing to take HIV+; no residential hospice
Practical & Emotional Support	Established community-based organizations with large volunteer pool	Newly organized AIDS Project using hospice for volunteer training
Other	Established education and prevention program; transportation services, residential facilities	Newly organized education program; some transportation services through new AIDS Project; no residential facility

Santa Cruz Plan and Reality

Despite the difference of Santa Cruz from San Francisco in regard to lack of AIDS expertise and resources, the Office of AIDS was only able to fund AIDS case management in Santa Cruz County according to the model that was woking in the existing big city projects.

In addition, because of the small proportion of the state's AIDS patients diagnosed in Santa Cruz County, Santa Cruz Hospice was initially funded to case manage only six patients. This meant authorization for a 1/5-time project director, a 1/3-time nurse case manager, and a 1/4-time social worker. Finding qualified professionals willing to accept part-time positions was the first obstacle Hospice faced in establishing an AIDS case management program in Santa Cruz County. The solutions were varied: the Hospice executive director added the project director duties to her already full-time position; Hospice contracted with a professional nursing corporation on a per-hour basis to obtain part-time services of a nurse case manager meeting the specifications of the Office of AIDS; it was impossible to fill the 1/4-time social work position. (Only after the Office of AIDS increased the social work position to 1/2-time was it possible to find a social worker who would accept the position.)

Hospice also received some funds from the state Office of AIDS for patient care services and planned to use these funds exclusively for patient rent supplements and to purchase food through the local food bank and home-delivered meals program. The plan was to provide attendant services for patients through a combination of volunteers from the Santa Cruz AIDS Project (SCAP) and the In-home Supportive Services (Medicaid attendant) program. It was also anticipated that skilled home care would be reimbursed through existing sources—Medicare, MediCal, and private insurance—and provided by existing home care agencies.

Implementation of this plan quickly revealed the shortcomings. First, SCAP was not able to provide sufficient volunteers to meet attendant care needs, and the reimbursement from In-home Supportive Services was not high enough to interest workers in caring for the AIDS patient. The case manager then turned to the private home care sector and found that registries had no attendants available who were willing and trained to care for AIDS patients. With permission of the Office of AIDS, Hospice became a direct provider of attendant services on an interim basis—recruiting, training, scheduling, and supervising a small group of attendants. The project director worked with SCAP to build the organization's direct service capabilites—both volunteer and paid—with the objective of transferring the attendant program to that agency in the future.

Second, the local food programs proved inappropriate for the AIDS patient, who is typically young, living alone or in a two-adult household and often suffering from severe malnutrition and chronic diarrhea. The food bank features items appropriate for families—large loaves of whole grain bread, cereals, fresh fruits and vegetables, and snack items. The home-delivered meals program serves meals suited to the tastes of their geriatric clientele. The case manager changed the plan and began training Hospice volunteers in the nutritional needs of AIDS patients and the specific preferences of project patients; funding shopping trips to wholesale markets in the neighboring metropolitan area; negotiating bulk purchase of nutritional supplements with a local pharmacy; and contracting for special meals with a private food delivery service.

Solving the food and attendant care problems was easy in comparison to the impossiblity of finding appropriate housing—especially for dying patients without caregivers and for patients requiring supervised living due to AIDS dementia and/or substance abuse. Some patients requiring special residential services never left the hospital (*see* sidebar), others were discharged to unsafe living situations and quickly returned to the hospital. Although case management failed for these clients, the case manager helped organize an interagency group to plan a special AIDS residential program. At the same time the project director brought the problem to the attention of the county AIDS planning task force, local elected officials, and anyone who would listen.

Even where resources existed, simple coordination of services was not sufficient. Physicians, hospitals, home care and social service agencies were willing to care for AIDS patients but had little expertise or experience. For example, home health agencies were willing to provide home care services, but had only limited experience in high-tech care (administration of chemotherapy, blood products, continuous infusions through central lines) and no experience with administration of experimental drugs and protocols. Due to her clinical expertise, the case manager became the resource person for social and health service providers serving project patients; because not all local agencies are available for crisis management 24 hours a day, the nurse case manager assumed this responsibility in order to make a complex home care plan work.

The bottom line is that the California model, effective for AIDS case management in major metropolitan areas of California, did not provide an adequate level of case management for home care services for Santa Cruz County. However, despite the limitations, Hospice has been effective in providing an alternative to hospitalization for a small number of AIDS patients. Some of the success, one must recognize, is due to many uncompensated hours contributed by the project director and the AIDS case manager, and to Hospice's donation of staff and volunteer services, supplies, and funds.

An underfunded AIDS case management project has also created stressful ethical di-

lemmas for the Hospice organization. Unlike regular hospice services, Hospice cannot, with the current level of state funding, serve all eligible clients requesting case management services. Although funding has been increased from the initial level of six patients, the number of eligible patients on the waiting list still exceeds the number of patients on the project. The responsibility of deciding how already-scarce case management and home care resources will be allocated among AIDS patients in Santa Cruz has fallen on Hospice.

Hospice is now seeking additional funding in order to expand the number of patients that can be served and to fund a Santa Cruz model of AIDS case management.

Santa Cruz Model: The Ideal

It is important to note that the original 1987 Santa Cruz proposal called for case management of a minimum of 20 patients by an interagency team including at least a full-time nurse case manager, part-time social worker, mental health therapist, and a consulting physician. Funds were also requested to develop a county-wide consortium of service providers. Experience has confirmed the wisdom of this original concept.

Subsequent experience has enabled Hospice to define the Santa Cruz model of AIDS case management as follows:

AIDS case management requires regular assessment of the medical, nursing, psychological, and social needs of a patient, followed by the development, implementation, and monitoring of a multiservice plan of care. This involves referral and/or brokering of services, coordination of providers, and patient advocacy. Key components of effective AIDS case management include:

- clinical expertise;
- 24-hour nursing availability to manage medical and psychosocial crises;
- funding to provide needed services not reimbursed from other sources;
- funding for short-term loans to patients for unreimbursed health care (eg, dental care) or unusual living expenses; and
- administrative time to assist the community in developing needed health services and in creating linkages between them.

The standards of care are as follows:

1. A minimum of 20 patients—HIV positive and symptomatic—are needed to establish an effective AIDS case management program.

2. AIDS case management requires a fulltime project director in order to administer the project and to take leadership in community organization around AIDS services;

3. The minimum paid staff for 20 patients should be:

- one fulltime-equivalent nurse case manager (it is suggested that two nurses share this position in order to distribute on-call responsibilities);
- one half-time social worker; and
- two hours/week of medical consultation.

4. The case manager(s) should be a registered nurse with five years experience in home care and willingness to develop clinical expertise in AIDS treatment.

5. Funding should be available to provide an average of 40 hours/month of attendant services for each project patient.

6. Funding should be available to supplement food, housing, and utilities for 75% of project patients. (In Santa Cruz, with very high housing costs, this requires $400/month.)

Conclusion

The AIDS epidemic has focused new attention (and funding) on community case management. Home health and hospice agencies need to take this opportunity to demonstrate the effectiveness of AIDS case management. However, to be effective, a minimum standard of case management should be defined by each community based on the needs of AIDS patients, as well as on the level of health services and coordination already existing in the community.

In communities such as Santa Cruz, with no existing system of coordination among inpatient, outpatient, and community-based services, no special residential programs for AIDS patients, and little clinical expertise, effective case management requires additional time to create needed community-based services and educate providers on the care of the AIDS patient. Of course, more case management time means higher per patient case management costs. Therefore, home care and hospice agencies in communities like Santa Cruz must demonstrate the cost effectiveness of expanded models of AIDS case management and community-based services. □

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